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# Measurement and Prediction of Quality of Life of Persons with Spinal Cord Injury

by

Laura Anne May

A thesis submitted to the Faculty of Graduate Studies and Research in partial fulfillment of the requirements for the degree of Doctor of Philosophy

in

Rehabilitation Science
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# Dedication

To the three most important people in my life, my husband John, whose incredible patience and unwavering support and encouragement inspired me; and to my sons Andrew and Brody, their arrival during my graduate studies exponentially enhanced the quality of my life.

# Abstract

The first purpose of this study was to evaluate the substantive, structural and external validity of an existing measure of Quality of Life, the Ferrans & Powers Quality of Life Index (QLI) for persons with spinal cord injury. The second purpose was to determine the predictors of QOL from prospectively gathered database information. In Phase 1, to evaluate substantial validity, 11 individuals participated in "think-aloud" interviews to determine the "meaningfulness" of the items and to identify areas requiring modification. Free sort and ranking exercises of the items were used to evaluate the structural validity of the domains and scoring model. In Phase 2, to evaluate external validation, a priori hypothesis about the relationships between the modified QLI and five other measurements were examined with a separate sample (n=98). Exploratory factor analysis was used to evaluate the structural validity of the domains of the modified QLI. Phase 3 involved the determination of predictors of QOL using variables representing impairment, disability and handicap (n = 37). With respect to substantial validity, two items were added to the questionnaire and the wording of three items was modified. Phase 1 and Phase 2 data revealed that the domains of the QLI, although different than proposed by the test developer, reflected elements of the integrated theoretical framework of disablement and QOL. The contribution of the satisfaction and importance sections proposed by the scoring model was not completely supported by the data. Three of the five hypothesized relationships examining external validity were supported. None of the database variables were significant predictors of QOL. It is concluded that the modified version of the QOL questionnaire reflects the perspectives of individuals with spinal cord injury in so far as the sample interviewed is representative. The results of the structural

validity evaluation have implications for the use of domain subscores and weighted versus section scores. Contrary to previous research perceived control was not related to QOL as expected and this may reflect the individuals resolve to not allow uncontrollable situations affect how they view their lives. Finally, the lack of significant predictors of QOL reflects the limitations of using database information and also indicates the importance of considering psychosocial and environmental variables as predictors.

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# List of Abbreviations

| | |
|---|---|
| ASIA | American Spinal Injury Asociation |
| CPA | Canadian Paraplegic Association |
| F | Family Domain |
| FIM | Functional Independence Measure |
| H & F | Health & Functioning Domain |
| ICIDH | International Classification of Impairments, Disabilities and Handicaps |
| LOC | Locus of Control |
| LSIA-A | Life Satisfaction Index – A |
| LSQ | Life Situation Questionnaire |
| P & S | Psychological & Spiritual Domain |
| QLI | Quality of Life Index |
| QOL | Quality of Life |
| RNL | Reintegration to Normal Living |
| RSES | Rosenberg Self Esteem Scale |
| S & E | Social & Economic Domain |
| SCI | Spinal Cord Injury |
| VAS | Visual Analogue Scale |
| WHO | World Health Organization |

# I. The Problem

## Introduction

Of major concern to society is the quality of life that derives from surviving a medical event and the consequences of any subsequent disability. Whether rehabilitative care impacts quality of life (QOL) after disability is a question for which there seems to be no clear answer. Recently, there has been a shift in the overall goal of rehabilitation from the restoration of physical function to the improvement of the quality of patients' lives (Day, 1993; Wood-Dauphinee & Küchler, 1992). It would seem that an outcome measuring quality of life would be an important determinant of successful rehabilitation. The concept of quality of life has most often been correlated with objective indicators such as physical function, including level of injury, socio-demographic variables such as employment and education, as well as socioeconomic status (Clayton & Chubon, 1994; Siösteen et al., 1990a; Fuhrer et al., 1992; Stensman, 1994). It is recognized that the inference about an individual's QOL based on objective evaluation has limitations. The use of subjective indicators incorporating a person's perspectives would provide a better reflection of his/her satisfaction with his/her life situation. Gill and Feinstein (1994) note that many measures of QOL within the medical literature may miss the target as they overlook the subjective opinions of clients.

Whether objective or subjective information is sought, useful application of research results depends on the measurement instruments. Choosing a measurement tool demands a clear understanding of the theoretical framework in order to appropriately interpret the results. In essence the question is one of validation, examining the accuracy of the inferences made from the test scores (Cronbach, 1971). In a recent review article, Evans et al. (1993) noted a remarkable increase in the overall number of QOL studies, however, lack of rigorous research design and poor validity of measurements limit the ability to compare and make inferences. The implications of the test scores can only be interpreted in light of theory, which includes the construct that is being measured. This should be reflected also in the development and the validation of the measure. Evidence of validity is particularly important whenever an instrument is used in a new setting or with a different group of people than that for which it was originally developed (Streiner & Norman, 1989).

Studies of QOL involving individuals with spinal cord injury (SCI) reflect the lack of attention given to a guiding theoretical framework as well as the necessary validation of the tools with the population of interest. Measures of quality of life include: the Life Satisfaction Index A (LSIA) (Neugarten et al., 1961); the Quality of Life Index (Padilla & Grant, 1985); the Life Situation Questionnaire (LSQ) (Krause and Crewe, 1987); the Life Situation Survey (LSS) (Chubon, 1987); and various Visual Analogue Scales. With the exception of the LSQ and the LSS, many of the measures used were not developed for use with the SCI population and there is little evidence of the re-examination of reliability or validity when the measure is applied to a different population.

The validation study of the LSS is limited by a small sample and the lack of theoretical background (Chubon, 1987). Fuhrer et al. (1992) used the LSIA; an instrument developed for a different population and has justified this choice based on the ability to compare results with other research that has used the same tool. Considerable research has been published by the developer of the LSQ, developed for use with individuals with SCI however limited statistical evidence of reliability and validity for earlier studies is given and there is no methodological detail ( Krause & Crewe, 1991). Recently, a study incorporating factor analysis of the revised version of the LSQ has identified seven underlying dimensions of subjective well-being (Krause, 1998a). However, the purpose and underlying framework are not clear. This measure has been described inconsistently across studies as a measure of adjustment, quality of life and subjective well-being (Krause & Crewe, 1991; Krause, 1992, 1998b) and without explanation of a theoretical framework, the synonymous view of these terms is unclear.

An area of much interest has been the prediction of QOL from various objective and subjective variables. Most of the studies evaluate the predictive relationship in a cross-sectional manner. Few studies have used prospectively gathered information to predict QOL. If one benefit of prediction is to identify individuals with the potential need for further treatment and follow-up, it makes intuitive sense to examine the relationship prospectively. Regardless, the criterion measure of QOL needs to be appropriate and valid for the task. To date, the studies of prediction reflect the problems already mentioned and this limits the application of the results.

## Problem Statement

Within rehabilitation, the importance of measuring quality of life with persons who have disabling conditions is being explored. Given the connection between theory and measurement, the first purpose of this study was to examine the validity of a measurement of QOL within the context of a theoretical framework involving the disablement process and quality of life. The measurement chosen for validation, the Quality of Life Index (Ferrans & Powers, 1985), comes closest to espousing a modified theory of disablement and although the psychometric properties of this tool have been examined, validation of the measure with individuals with SCI has not been evaluated. After the examination of validity, the second purpose involved the determination of predictors of QOL from prospectively gathered data one-year post injury, using variables that are reflected within the theoretical framework of disablement.

## Significance

If the ultimate goal of rehabilitation is to enhance the quality of life of our clients we need to be able to measure if goals have been achieved. Measurement may also provide information about specific life aspects, allow the identification of problems areas, as well as plan and examine interventions to improve quality of life. To date, there is limited published information regarding the quality of life of individuals with spinal cord injury. Of the literature available, problems do exist. Often there is a lack of a theoretical framework and/or definitions of quality of life. In particular, the measurement tools either lack evidence of reliability and validity or they have been developed and examined with populations other than those with spinal cord injury. It is therefore difficult to determine if the instruments address the components of QOL that are meaningful to individuals with SCI. The determination of the validation of an instrument will ultimately lead to increased confidence in the inferences that can be made from the data collected among individuals with SCI. The examination of the prediction of QOL is enhanced when the criterion measure has been validated with the patient population in question. If predictors of QOL can be identified early, recognition of individuals in need of further follow-up after rehabilitation may be possible so that the ultimate goal of improved QOL can be realized.

## II. Review of the Literature

The literature guiding this study is complex and diverse therefore, will be addressed sequentially. The first section will address the theoretical frameworks of disablement and quality of life, which includes an examination of integrated frameworks used to guide the measurement validation. Following this, a discussion of the measurement of QOL will ensue with particular focus on the variety of issues that have bearing on the choice of instrument and the examination of validity. The literature review will then turn to an overview of the QOL research which focuses on individuals with SCI. Finally, the instrument that is used in this study, the Quality of Life Index (QLI), will be discussed.

### Theoretical Framework

Measuring QOL as a rehabilitation outcome requires a theory that encompasses the disablement process and quality of life. The theory of disablement has been a useful tool to guide the objective measurement of the consequences of disablement and the subsequent rehabilitation outcomes (Wagstaff, 1982; Whiteneck, 1994). It has been proposed that the evaluation of rehabilitation go beyond measures focused on dimensions easily objectified, such as physical function, to include quality of life as an outcome (Whiteneck, 1994; Wood-Dauphinee & Küchler, 1992). To include this concept will require re-examination of the theories and models currently used to guide rehabilitation outcomes.

It is generally agreed that quality of life is multi-dimensional and complex (Ferrans, 1992; Hawthorn, 1993). However, there is much confusion surrounding the components that make up quality of life. The existence of so many models indicates that there is hardly agreement as to what components constitute the dimensions of QOL. Accurate measurement is further plagued by the use of indices constructed with the use of pre-conceived models based on the researcher's perspective which often reflects their particular discipline (Day, 1993; Hunt, 1997). A more acceptable approach would encompass a model that includes the individual's appraisal and perceptions of his/her quality of life (Cella, 1992; Zhan, 1992).

In the literature, quality of life of individuals with spinal cord injury has been studied within the context of life satisfaction, subjective well-being and adjustment (Buckelew et al.,1991; Fuhrer,1994; Stensman,1994). When theory is implied, the underlying conceptual framework has varied. Much attention has been given to the stage theory of adjustment whereby an individual comes to terms with their situation by progressing through a number of stages such as shock, denial and depression (Buckelew et al.,1991; Trieschmann, 1988). Others have suggested the use of the theory of disablement incorporated within the World Health Organization's classifications of impairment, disability and handicap (Fuhrer et al.,1992; Whiteneck,1994).

Among the difficulties of using stage theory as a working framework to interpret quality of life is that there is no research evidence of the existence of these individual stages (Trieschmann,1988). Also, research is often confined to the time shortly after injury focusing on coping mechanisms used during this period, when individuals are most powerless and the level of stress and confusion is likely to be high (Carpenter,1994). Oliver (1988) suggests that this view of spinal cord injury as a "personal tragedy" leads to a two-tier categorization: those who succeed and cope with the injury or those who succumb to the "tragedy" of disability.

The strength of using the model of disablement according to Whiteneck (1994) lies in the logical connection between rehabilitation interventions and the ultimate concern with quality of life. Fuhrer (1994) recognizes the implications for the use of the model of disablement however, he points out that there are needed developments to elaborate the subjective and personal value aspects of impairment, disability and handicap. An all-inclusive theory requires understanding of the conceptualization of quality of life as well as the disablement process. This background information can elucidate the consolidation of the two concepts within one framework.

### *Models of Disablement*

Rehabilitation professionals need theory to guide and advance practice and research as well as to aid in communication between each other and with the consumer (Wagstaff, 1982). Fundamental to the development of theory is clarity and consistency in the definition of important concepts which can guide the choice and design of relevant outcome measures (Minaire, 1992). The global term of "disablement" reflects all the diverse consequences that disease, injury, or congenital abnormalities may have on human functioning (Jette, 1994). There have been a number of conceptual schemes or models that have been developed to guide disablement research and outcomes.

Two schemes have been foremost in the discussion of disablement. The first was a model developed by a sociologist, Saad Nagi (Nagi, 1965), the second is the International Classification of Impairments, Disabilities and Handicaps (ICIDH) developed for the World Health Organization (WHO, 1980). The four components of each of these models resemble one another, as demonstrated by figure 2-1. The basic goal of both schemes is to delineate the major pathways from disease to the variety of consequences that may result. One of the key applications of these models is the ability to identify and objectively measure the consequences.

There is general agreement between the two schemes in regard to the first two components of the models. Both active pathology and disease refer to the disruption of normal physiological, biochemical or anatomical processes and the simultaneous attempts by the body to regain homeostasis. Similar to each model, impairment refers to abnormality at the body systems level resulting from any cause, which may involve psychological, physiological or an anatomical structure or function. An impairment represents deviation from some norm in the individual's biomedical status (WHO, 1980). A subclass of impairment that is included in the Nagi (1965) model involves congenital loss or abnormality that is not associated with active pathology. This reflects a subtle difference in viewpoint for this part of the framework. The WHO model views impairment as the "exteriorization" of active pathology, when the individual becomes aware that he is unhealthy.

It is at the level of the individual where these two schemes diverge in their use of the terminology. Nagi (1965) uses the term "functional limitations" to represent restrictions in performance at the level of the whole person. This concept of attributes, involves indicators which are reflected in the characteristics of the person (Nagi, 1991). It is important to note that limitations in function at the person level may result from differing impairments and limitations at lower levels. For example, the inability to lift heavy objects may be related to mechanical problems in the lower back or it may be a result of diminished cardiac or pulmonary function. In the Nagi scheme, "disability"

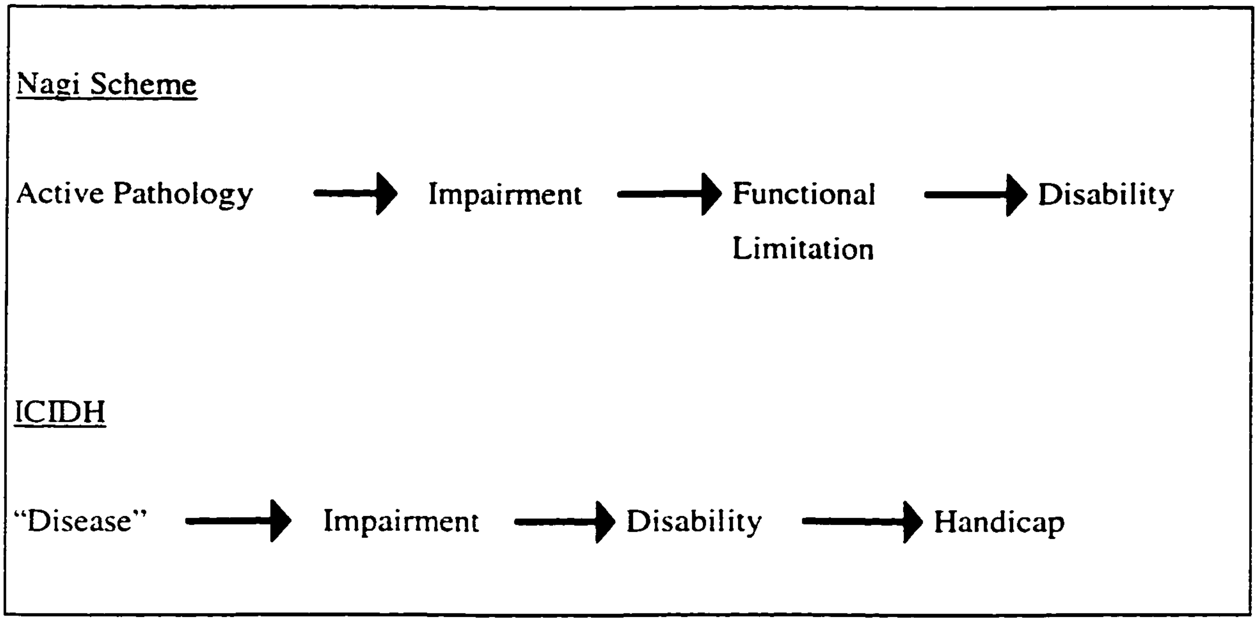

**Figure 2-1** Two conceptual schemes for the disablement process

represents a relational concept that cannot be solely accounted for in the attributes of the individual (Nagi, 1965). This term is used to assess the individual's capacities to perform socially defined roles expected within a given socio-cultural and physical environment. These roles are organized into spheres of life activities such as those of family, other interpersonal relations, employment, education, recreation and self-care. In addition, "disability" includes subjective aspects as defined by the individual and others and the effect of environmental barriers. An example of an application of these terms would include gait restrictions as a "functional limitation" and the inability to perform personal care or occupational activities as a "disability".

In the ICIDH, the term "disability" is defined as the lack of ability to perform an activity which would be considered normal for that person (WHO, 1980). Within this framework, functional limitation is regarded as an aspect of impairment which is concerned with individual functions of the body (WHO, 1980). Thus, functional limitations are conceptualized at the organ level rather than the level of the whole body. "Disability" in this scheme is concerned with activity restriction of the person, some indicators include locomotion, personal care, family and occupational roles. These indicators are noted at the level of the person and are objectifiable in that the functional limitation expresses itself as a reality in everyday life, no reference to others is made. Some of the indicators here are said to be referential within the concept of "disability" in the Nagi model. For example, personal care is viewed as a component of a role or multiple roles and limitations in performing such tasks often results in reciprocal role relationships of dependence (Nagi, 1991).

The final element of the disablement process in the ICIDH scheme is "handicap". This term represents the disadvantage for a given individual resulting from the presence of impairments or disabilities which limits the fulfillment of normal roles (WHO,1980). As opposed to the assessment of the individual's abilities in relation to relevant aspects of their situation, handicap is a consequence based on the circumstances of the disabled individual that place the person at a disadvantage relative to other people. Handicap thus reflects the value society attaches to the disability (Wagstaff, 1982). Categories of handicap include: orientation (to surroundings), physical independence, mobility (in his/her surroundings), occupation (ability to occupy time - work and recreation), social integration (participate in customary social relationships), and economic self-sufficiency (WHO, 1980).

Within rehabilitation science, it is the WHO model of disablement that has been widely accepted as the basis on which to build a model of rehabilitation outcome measures for assessing the disablement process (Minaire, 1992; Whiteneck, 1994). The main advantage of this scheme, is that it provides a common language which can serve as a foundation for disablement research. This model is not without need for improvement. In particular, there have been criticisms regarding the lack of emphasis on the role of the environment, failure to identify the causes of the limitations in social performance, and the difficulty distinguishing some consequences that may be classified under both the disability and the handicap concepts (Jette, 1994; Minaire, 1992). Fuhrer (1994) sites the need for the elaboration of subjective and personal value aspects of impairment, disability and handicap in order to link these concepts to other rehabilitation outcomes that are subjective in nature, such as QOL.

These are not the only two models documented to describe disablement and identify outcomes. Minaire (1992) combined four theoretical models, which complement each other to describe a unifying schema of the disablement process. The four models included the ICIDH as well as the biomedical model, based on the concept of disease in which the outcomes measured involve the identification of diagnosis, symptoms and other physiologic or economic indicators. The third model of situational handicap views disablement as a process dependent on life situations, all of which include different aspects of the environment. Measurement is directed toward the individual biomedical, psychological and social processes, the disabling situations and the environment. The fourth model incorporated into the schema is the quality of life model. The QOL model is described in terms of two frameworks, the relationship of QOL to handicap in the ICIDH model and the overlapping stages of disease, personal functioning, social, psychological and role status and health perception. The application of these four models to the unifying schema to direct outcome measurement and interventions reflects Minaire's definition of the disablement process as "a synthesis of medical, sociological, and anthropological analyses of individuals and their activities."

Although not necessarily discussed as theories of the disablement process, additional models have been identified that help to illustrate the complexity of this process and the identification of outcome measures. Short (1981), supports the holistic approach which includes awareness of the functional interdependence of psychological, physical, social and vocational factors. Rehabilitation measures that focus on the whole person, will assist in the application of treatment aimed at the individual's needs within a broader framework. The biopsychosocial model described by Engel (1982) closely resembles the holistic approach and provides a framework for outcome measures based on three major dimensions. The physical function component encompasses the individual's performance of daily activities; the psychological component consists of a variety of cognitive, perceptual and personality traits; the social component is viewed as the interaction of the individual within a larger social context or structure. All three components interact with one another and alteration within one component may affect another thus reflecting the necessity for a global assessment of the individual in order to understand the disablement process.

Understanding the complex process of physical disablement is essential for the design and use of rehabilitation outcome measures. As demonstrated, there is yet to be the universal acceptance of a singular conceptual model, which will establish a commonality for disablement research. As stated previously, it has been suggested that quality of life be included as an outcome measure to globally assess the disablement process. To view quality of life as an integral component of rehabilitation outcome assessment requires understanding of the conceptualization of QOL and its alignment with the concepts of disablement models.

### *The Conceptualization of Quality of Life*

Just as there is difficulty in describing a universally accepted model of the disablement process, the conceptualization of quality of life is even more diverse. Although it is generally agreed that the concept is multidimensional and complex, the definitions and terminology vary significantly. The question remains if the concept of quality of life, regardless of how it is defined, can fit with one or more of the presently described models of disablement. Or could it be that quality of life is a phenomenon that requires an entirely new model to guide rehabilitation researchers in their quest to measure this concept.

In the literature, the definition of quality of life remains elusive. No unified approach has been devised for its measurement, and little agreement has been attained on what it means (Gill & Feinstein, 1994). In some cases the conceptualization of QOL has been based on the available instruments rather than theory (Hunt, 1997). Often in the medical literature, the term quality of life is substituted for other terms intended to describe a patient's "health status" or has been described by such attributes as life satisfaction, well being, health, happiness, self-esteem, meaning of life and functional status (Gill & Feinstein, 1994; Zhan, 1992). Due to the stringent conditions of the scientific method, often the concept of quality of life is defined in terms of objective indicators such as level of education, financial status, housing, employment and physical function (Day, 1993; Zhan, 1992). In reality, the separation of the effects of health on QOL and the accompanying effects of finance, family life, responsibilities, friendship, occupation and so on, is virtually impossible (Hunt, 1997). In fact, one of three new themes for 1999 research grants proposed by the Social Sciences and Humanities Research Council (SSHRC) has recognized the need to examine the social, cultural and economic factors that are related to and influence health.

In the medical literature there is often no distinct or unique meaning for the application of the term "quality of life", which hinders the comparison of studies (Gill & Feinstein, 1994). Beckmann and Ditlev (1987) note that some investigators measure quality of life without having defined it, rationalizing that the issue deals with invisible quality of life concepts and thus it is theoretically impossible to define. In contrast, many authors have attempted to define the concept. Following are some of the definitions from the literature. It is evident that they reflect the breadth and diversity of this concept.

> "Quality of life is defined as 'happiness', the conditions for happiness involve the concept of freedom, the ability to choose and realize one's goals" (Beckmann & Ditlev, 1987).
>
> "A cognitive experience manifested by satisfaction with life domains of importance to the individual and an affective experience manifested by happiness with important life domains" (Oleson, 1990a).

"The degree to which a person's life experiences are satisfying" (Zhan, 1992).

"Refers to the patients' appraisal of and satisfaction with their current level of functioning compared to what they perceive to be possible or ideal" (Cella,1992).

" a dynamic concept that includes all the experiences of an individual's life and can be described only by the individual." (McDaniel & Bach, 1994).

"An individuals' perception of their position in life in the context of the culture and value systems in which they live and in relation to their goals, expectations, standards and concerns" (The WHOQOL group, 1995).

"A person's sense of well-being that stems from satisfaction or dissatisfaction with the areas of life that are important to him/her" (Ferrans, 1996).

A common theme among these definitions centers on the individual's appraisal of the situation, an indication that QOL cannot be evaluated simply by objective indicators. The subjectiveness of this concept reflects the uniqueness of meaning of QOL, as different as each person. It may be perceived that the boundaries of this concept are too vague to identify a suitable model or even be considered appropriate for measurement. Similarly, questions may arise surrounding the construction of a definition to fit the theoretical model employed by the investigator.

An individual's assessment of their QOL will cover many aspects of life. Calman (1987) provides a general discussion of dimensions related to physical problems, psychological, social and spiritual factors as well as other broader dimensions such as culture or politics. The following discussion deals with the varying dimensions that have been described in the literature. Although there are often common elements, it is clear that there is no universal conceptualization of the aspects of life that make up this construct.

Based on his own research and the analyses of other researchers with multiple patient groups, Hörnquist (1989) proposes a six-domain conceptualization of QOL. The biological domain is concerned with various bodily functions which includes symptoms and pain, side effects and injury healing. Self-concept, learning, creative ability, and memory are some of the aspects of the psychological domain. The social domain refers to social contacts in general involving family, friends and includes sexual life as well. The capacity for personal care, mobility and work represent the behavioral/activity domain.

The material domain includes material assets, residence, and income from any source. The structural domain incorporates the individual's position in society as well as their view upon society intended to be a reflection of life meaning.

Cella (1992) reviews four primary dimensions of quality of life supported in the oncology literature. Although the concept and dimensions of QOL focus on oncology, the author states that the discussion also applies to other chronic or life threatening conditions. Physical well being has to do with perceived and observed bodily functions. Functional well being refers to one's ability to perform activities related to personal needs and social roles. Emotional well being is a reflection of both positive and negative affect. The content of the social well-being dimension is diverse ranging from perceived social support, leisure activities, relationships with family and friends as well as sexuality. It is noted that not all important areas are captured within this four-domain scheme. For example, spirituality is excluded by the author as a component of quality of life for the reason that it is too distinct a domain, despite the belief that it is an important element to many people.

In a general discussion of the conceptual and measurement issues surrounding QOL, Zahn (1992) presents four aspects that represent dimensions that are essential for an assessment of quality of life. The first aspect, life satisfaction, is a cognitive evaluation that is derived from an individual's comparison of aspirations and achievements. Life satisfaction is influenced by multiple factors including personal characteristics and external conditions and changes in any of these conditions can alter the individual's perception. The second aspect is labeled self-concept/ psychological well being which reflects a cognitive component involving the individual's own beliefs and feelings about themselves. The health and functioning aspect of QOL encompasses social and personal matters and should be evaluated with consideration of environmental, societal and political influences as well as the objective phenomena of physical status. The discussion of the final aspect socio-economic, focuses on the contribution of socio-economic status (SES) to QOL. Although often defined objectively in terms of occupation, education and income, the subjective evaluation of perceived adequacy of these resources needs to be considered.

The World Health Organization (WHO) has initiated a project to develop an international QOL assessment (WHOQOL Group, 1995). The development process involved a stage to clarify this concept and identify the multiple dimensions using multi-cultural focus groups that included healthy individuals, individuals with disease, and healthcare professionals. Six broad domains have been recognized as reflecting the multi-dimensional nature of QOL. These are: physical; psychological; level of independence; social relationships; environment; and spirituality/religion/personal beliefs. Each of these broad domains includes facets that summarize that particular domain.

The results of extensive literature review and research evaluations with healthy individuals and patients undergoing hemodialysis has lead to the development of a four domain model by Ferrans (1996). The greatest numbers of items are contained within the health and functioning domain. This domain includes life aspects such as physical independence, pain, stress or worries, leisure time activities, control over life and potential to live a long time, to name a few. The psychological/spiritual domain includes items relating to happiness and satisfaction, achievement and peace of mind/faith. In earlier publications (Ferrans, 1990b) the third domain was labeled socioeconomic but is now being referred to as the social and economic domain (Ferrans, 1996). Perhaps the previous label emphasized the elements related to financial concerns such as standard of living and jobs and did not clearly indicate that social items such as friends and emotional support were also part of this domain. The final domain, family includes four items regarding family, spouse and children.

Although the model includes many of the domains previously described, Wood-Dauphinee and Küchler (1992) discuss these domains within three dimensions of QOL. The dimension of "experience" encompasses physical and psychological status as well as interpersonal relationships with others. Also part of this dimension is the socio-economic domain, which not only considers financial situation but also the environment, leisure time and work performance. The spirituality domain encompasses religious beliefs as well as the moral and ethical beliefs that may act as surrogates for religion. The context of family, social group and cultural or political backgrounds are domains found in the "reference" dimension. Although mentioned as a factor influencing the evaluation of QOL in other reports, these authors actually include a separate time dimension.

Time as a distinct dimension of QOL is often neglected yet is quite important. It can be viewed as the connecting thread of many, if not all of the dimensions discussed (Calman, 1987). The time dimension suggests that QOL is a culmination of past and present experiences as well as giving consideration to goals for the future (Campbell et al., 1976; Wood-Dauphinee & Küchler, 1992). In fact, time may change the evaluation of QOL. As persons grow older, their hopes, aspirations and expectations of life will change. This is a critical element to consider when defining and measuring QOL. Although the level of satisfaction with a life domain may not change, the perceived importance of the domain may change thus changing an individual's overall perception of their QOL.

It appears that quality of life is not only related to an individual's perception, but covers many aspects of life and may change with time. Calman (1987) identifies several implications that follow from this conceptualization of QOL. Evaluation of QOL which depends on past and present experiences as well as future hopes can be described and measured only in individual terms. Many aspects of life need to be considered with separate goals and achievement of these will be reflected in improvement. Illness and treatment may modify these goals. Personal growth and development can be realized when the gap between hopes and actual achievement is narrowed. This summary of the conceptualization of QOL basically reflects a goal-oriented approach and should fit well within the disablement process, the model guiding rehabilitation outcomes.

### *QOL and Disablement: An Integrated Model*

If the ultimate goal of a comprehensive rehabilitation program is the attainment of an optimal level of independent living and quality of life (Crewe, 1980; Noreau & Shephard, 1995; Wood-Dauphinee & Küchler, 1992), then it is necessary to clearly understand the connection between the concept of QOL and the disablement process. The targets of the rehabilitation process include physical, social-psychological and community reintegration issues. These issues, also part of the concept of QOL, can be represented within a model of disablement. It seems logical that minimizing disablement as represented by the development of impairments, disability and handicaps, will ultimately lead to an improved quality of life. To understand this relationship it is necessary to have a clear picture of an integrated disablement model, one that includes quality of life. In the literature, QOL is most commonly associated with the Nagi or ICIDH representation of the disablement process. Various approaches have been taken and there appears to be no universal acceptance of one integrated model.

Jette (1994) discusses the modification of the disablement schemes including the model of Pope and Tarlov (1991), and notes that some argue that QOL is a concept distinct from other disablement components. Although the concept of QOL is broader than disablement, some of the components such as physical functioning, social interaction and emotional status clearly overlap those included in the disablement model as defined by Nagi. Jette (1994) considers an overlapping relationship of quality of life to the disablement concepts as illustrated in figure 2-2.

Other authors have either extended the ICIDH model or incorporated it into a modified model of the disablement process. As described previously, Minaire (1992) proposed a unifying schema of the disablement process that incorporated four models. Within this representation of disablement (figure 2-3), the biomedical model embraces the items on the right; the ICIDH model is focused on the lower half of the diagram; the situational handicap model covers environment, handicaps and disabilities; and quality of life is encompassed within handicap. Disability and handicap are viewed as endpoints in the disablement process and therefore within this model, quality of life would not be seen as an integral part of the process.

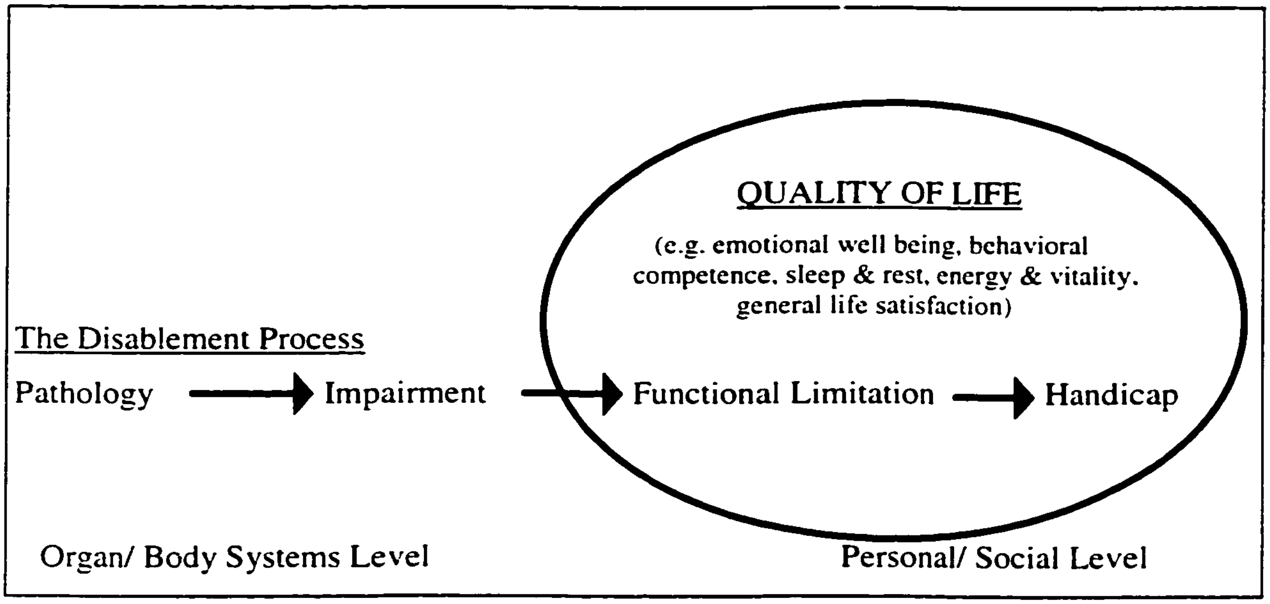

**Figure 2-2** Relationship of QOL to the disablement concepts. (Jette, 1994)

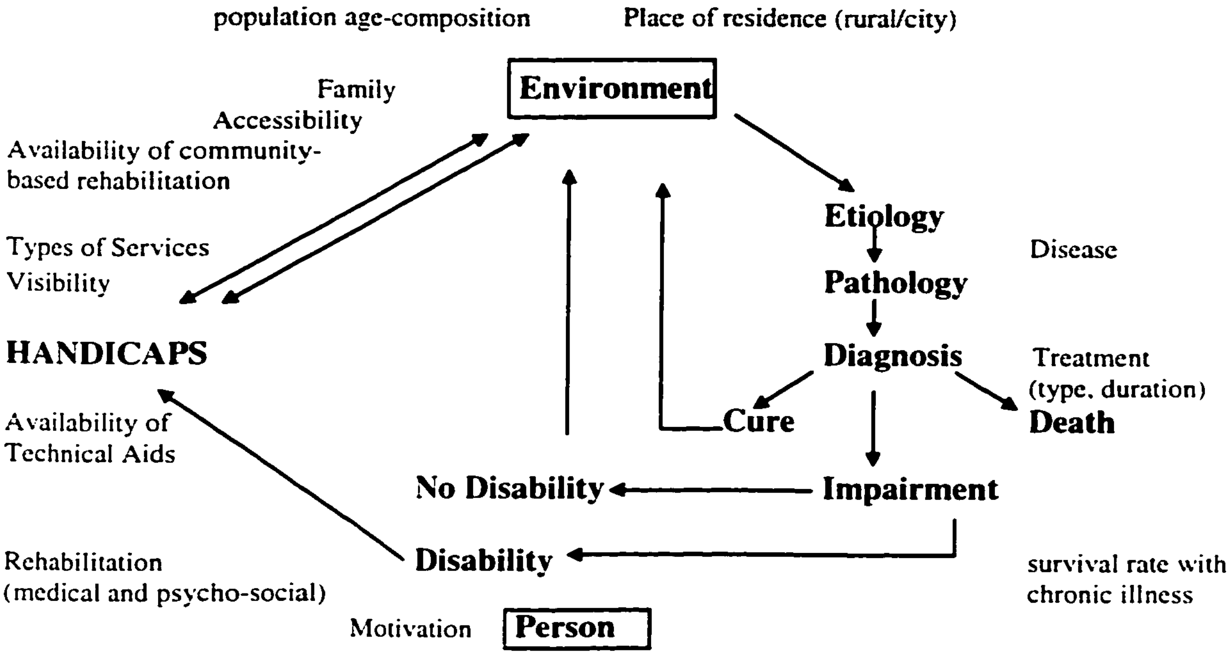

**Figure 2-3** Unifying schema of the disablement process (Minaire, 1992).

Whiteneck (1994) presents a model (figure 2-4) of rehabilitation outcomes which extends the concepts of the ICIDH model to include quality of life so that the subjective perceptions of persons with disability are recognized. Within this conceptualization, greater emphasis is placed on the understanding and measuring of handicap, however the author does not detail the contribution of rehabilitation interventions, societal limitations and individual characteristics to the minimization of handicap. An important addition to this model is the recognition of the lifetime nature of disability as represented by the secondary conditions. Here, QOL is viewed as a rehabilitation outcome assessed by the individual's perception of each condition. It appears that quality of life is an endpoint and the model does not attempt to explain the existence of possible reciprocal relationships. Noreau and Shephard (1995) have advocated this model as a suitable framework to document the objective and subjective benefits of exercise and sport and their influence on quality of life.

Although not an extension of the ICIDH, the model of health related quality of life proposed by Wood-Dauphinee and Küchler (1992) incorporates the World Health Organization definition of health as physical, emotional, and social well-being (WHO, 1958). Health related QOL is represented as the individual's perception of their functioning and role performances within the physical, psychological and social domains, after taking into account the effects of disease and treatment. This conceptualization also indicates that the patient's perception is the endpoint of a primarily hierarchical model, bi-directional arrows are only present between the three domains.

Pope and Tarlov (1991) have built on the conceptual frameworks of Nagi and the WHO, to develop a model of disability that depicts the influence of specific risk factors and the relationship of the disabling process to quality of life (figure 2-5). In this model, risk factors can predispose an individual to the disabling process, can interact at different stages of the process and can exist internally (personal choices) or externally (environment). The components of quality of life include the performance of social roles, physical status, emotional status, social interactions, intellectual functioning, economic status and self-perceived or subjective health status. Quality of life is relevant at all stages of the disabling process, the arrows indicating a reciprocal relationship, such that QOL is an integral part of the process rather than an endpoint.

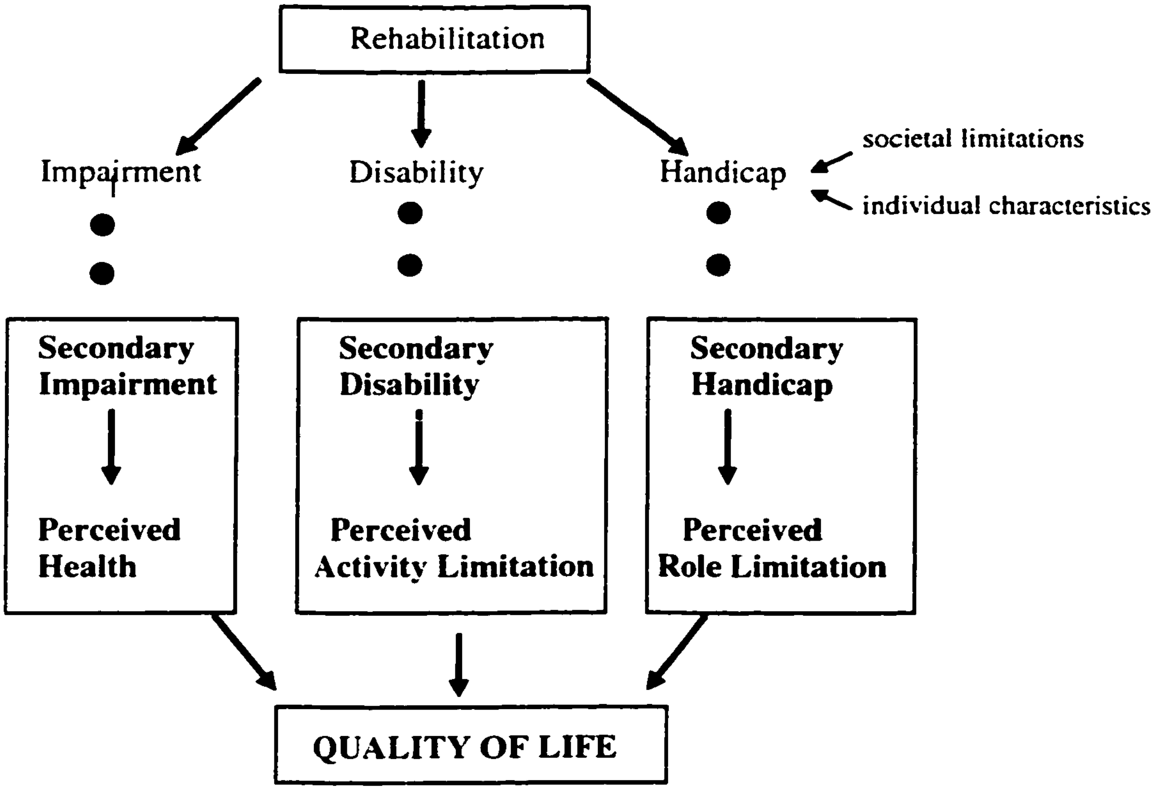

**Figure 2-4** A Model of Rehabilitation Outcomes (Whiteneck, 1994)

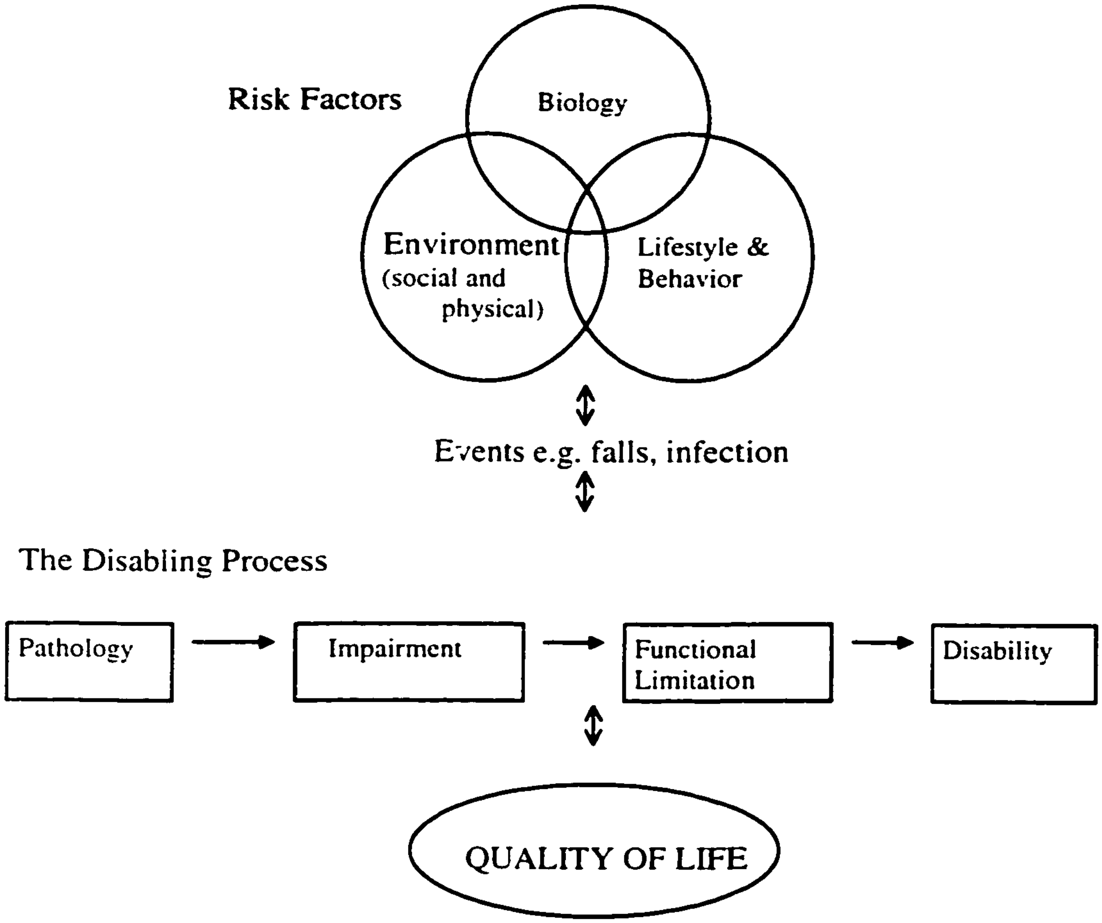

**Figure 2-5** Model of Disability (Pope & Tarlov, 1991)

A further extension of the disablement process is primarily based on the Nagi scheme but also includes some of the ideas and elements of the ICIDH (Verbrugge & Jette, 1994). They have introduced the concepts of risk, buffer and exacerbating factors, which can act to modify the main pathway at any level. Similar to the model of Pope and Tarlov (1991) risk factors are included as behaviors or attributes that exist at or before the outset of the disablement process and are thus placed at the left side of the model (figure 2-6) to note their predisposing nature. The interaction of risk factors at different stages of the disablement process in the model of Pope and Tarlov (1991) is similar to the concept of buffers in this model. Buffers reflect interventions aimed at reducing the progression of the main pathway and can operate at any point throughout the disablement process. Interventions that act as buffers can be intra-individual factors reflecting actions taken by or operating within a person, or extra-individual factors which are performed or exist outside of the person. Exacerbating factors can be intraindividual or extraindividual, such as when interventions do not work as expected, persons adopt behaviors or attitudes that perpetuate their limitations and disability, or societal barriers prevent the fulfillment of wants and needs. As an additional element, the disablement process can affect quality of life and is conceptualized within the model as a global outcome of wellbeing, happiness and life satisfaction situated as an endpoint to the right of disability, the final concept of the main pathway. Interestingly, a footnote to the situation of QOL in this model, points out that Pope and Tarlov (1991) place QOL in a more ambiguous position.

The conceptualization of quality of life as a part of the disablement process does appear feasible and desirable in order to direct rehabilitation evaluations. McKenna (1993) asserts that therapists may make generalized assumptions about what measures and interventions are best for the client based on a set of predetermined judgments about the composition of good quality of life. These judgments may be a result of the knowledge and belief in models that emphasize objective outcomes to assess the disablement process. To determine quality of life, the subjective perception of the life experience should be included. Although the objective indicators stressed by the current disablement models describe conditions that have an impact on the life experience, they do not directly assess the individual's experience.

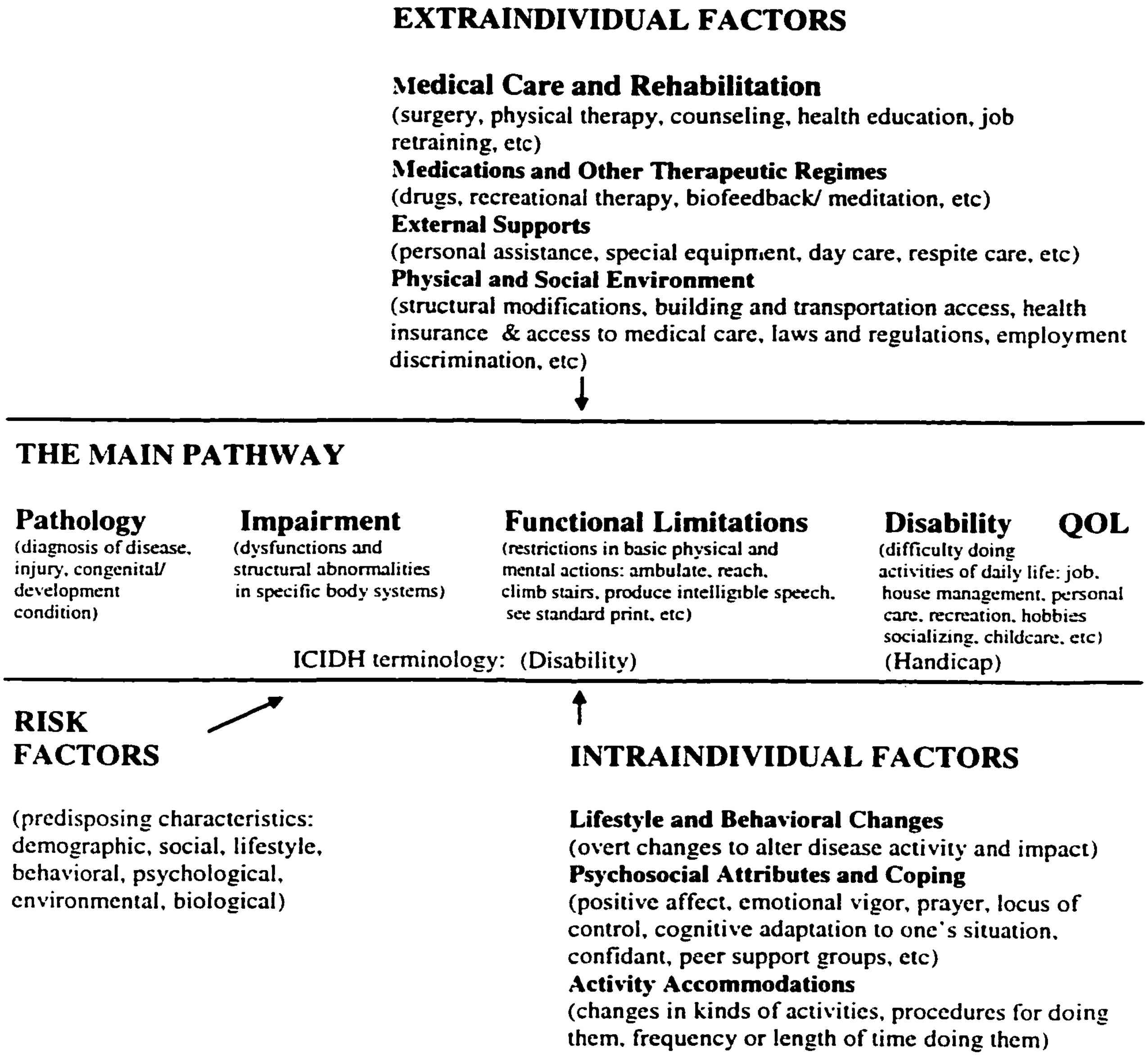

**Figure 2-6** A Model of the Disablement Process (Verbrugge & Jette, 1994)

Recognizing this, the question remains as to which path to follow. Should the current disablement models be modified as suggested by Whiteneck (1994) and Jette (1994), to include the concept of quality of life? Would it be more acceptable to combine selected models demonstrated by Minaire (1992), to form a unifying schema of the disablement process? The difficulty remains as to how quality of life can be included as an outcome measure in disablement research. It is evident that both the subjective and objective aspects of this process need to be included if quality of life is to be viewed as a rehabilitation outcome for clinical and research applications. The usefulness of the results of studies measuring QOL in rehabilitation may be limited if the investigators neglect to review the nature of the concept and its incorporation within a disablement model.

To provide a solid basis for the development and interpretation of this study, a choice was made to use one integrated model as the guiding framework. It was determined that the integrated model should go beyond the factors that focus only on the health status of the individual. The model needed to include intrinsic and extrinsic, subjective and objective factors beyond health, that could influence the disablement process as it is almost impossible to separate the effects of health on QOL from effects such as finance, family and occupation to name a few (Hunt, 1997). Another issue to consider is the situational relationship of QOL and the disablement process within the integrated model. If the concept of QOL is an interaction between the individual and his/her life situation, then it would be best to view QOL as having an overlapping or reciprocal relationship with the disablement process rather than an outcome of disablement. However, if quality of life is viewed as an outcome of the individual's experience of disablement, as conceptualized in this study, then the positioning as proposed by Verbrugge and Jette (1994) would fit best. In addition, all levels of the disablement process should be included in the model so that the individual's appraisal of all possible situations can be considered as affecting or being affected by QOL.

Each of the integrated models presented has benefits and deficits in the provision of a theoretical basis in which to evaluate the measurement of QOL for individuals with disabilities. The model of Jette (1994), although implying a reciprocal relationship between QOL and disablement, does not include the level of impairment, which for some individuals could profoundly influence life experiences. A meta analysis of the effects of the disablement components has shown that the relationship between impairment and QOL is weak, however methodological problems of the studies reviewed indicates further investigation is warranted (Dijkers, 1997). Minaire (1992) indicates that within the unifying schema, QOL is focused on handicaps only. In addition, the factors considered to modify the disablement process are mostly objective and external with little elaboration of the personal factors other than motivation. The models proposed by Wood-Dauphinee and Küchler (1992) and Whiteneck (1994) view QOL as an outcome or endpoint, which considers the individual's perception of their function. Although this is desirable, the contribution of outside factors to the individual evaluation of QOL is not well expanded. The models of Pope and Tarlov (1991) and Verbrugge and Jette (1994) are very similar and could both provide the guiding framework for this study. Verbrugge and Jette (1994) consider QOL as an outcome of the disablement process, and provide more detail about the potential intrinsic, extrinsic, subjective and objective factors that can influence the process. This greater detail allows clearer identification of important variables for the evaluation of the measurement instruments.

## Measurement of Quality of Life

The approach toward the measurement of QOL has varied in the literature but the common thread indicates the measurement to be either subjective or objective. Different tactics have been employed to measure subjective QOL, which centers on the subject's description of the quality of his or her life experiences. The simplest instruments involve the scoring of a single item such as, " How would you rate your current QOL?". This method has been used in a variety of studies with SCI individuals (Coyle et al., 1994; Cushman & Hackett, 1992; Siösteen et al., 1990a; Stensman, 1994). The single question may differ slightly in the wording across studies and the method of scoring may use either Visual Analogue Scales (VAS) or Likert scales. Another commonly adopted method involves the rating of a multiplicity of items targeting the concept of life satisfaction (Clayton & Chubon, 1994; Nieves et al., 1991). Subjectively perceived QOL can also be measured by asking individuals about the importance they give to life dimensions (Whiteneck et al., 1992). The objective measurement of QOL usually involves indicators of physical health, mental status, socioeconomic status, education and occupation (Ferrans, 1985; Noreau & Shephard, 1995). The inference made when evaluating objective indicators is that the better one's achievement in the measured domain, the better will be his or her QOL (Clayton & Chubon, 1994). Campbell et al. (1976) has pointed out that objective indicators measure things that influence the life experience and should be considered as surrogate measures of the concept. Measurement of the subjective and objective indicators of QOL is important and an integrated model of disablement that includes QOL appears to take this into consideration. Understanding the link between the objective and subjective indicators is essential for a credible rationale for rehabilitative treatments in the enhancement of QOL for patients. This understanding can occur when measures are validated within the context of an underlying theoretical framework.

Comparison of the research literature is made difficult by the varied methods used to measure quality of life. Other problems include the lack of a conceptual framework or the incomplete description of the psychometric properties of the measure used in the study. The intended purpose of the tool should also be considered. There seems to be no clear consensus regarding the use of generic versus disease specific measures. The scoring procedures vary among the numerous measures and this has direct impact on the ability to make inferences from the results. Given the multitude of instruments claiming to measure QOL, whether subjective or objective, it is not surprising that there are concerns regarding the measurement of this multidimensional construct.

Regardless of definition or guiding framework, it is important to recognize that it is the instruments used to measure QOL that ultimately define this concept in any given clinical or research situation (Ferrans, 1990a). Thus it becomes critical to carefully examine the instruments themselves and the evidence of validity to determine how well they capture the chosen definition and framework. Evaluation of the validity of an instrument can be considered with respect to the intended purpose of the tool. Kirshner and Guyatt (1985) discuss three applications of health status measures: discrimination, prediction and evaluation. A discriminative index is used to distinguish between individuals or groups based on the existence of certain characteristics within an underlying dimension. A predictive index is used to classify persons into categories based on what is expected regarding future outcomes. An evaluative index is used to measure the magnitude of change over time in an individual or group on a specific dimension of interest. The intended purpose of the instrument has implications for development of the tool and assessment of psychometric properties which is considered within the traditional context of the three C's: content, criterion and construct validity.

The important point is that the validation of an index for one purpose does not necessarily ensure that it can be used for the remaining ones. Of concern for the predictive tool is criterion-related validity (Kirshner & Guyatt, 1985). Criterion related validity includes concurrent and predictive validity. Concurrent validity refers to the extent to which the instrument produces the same results as the gold standard, or criterion measure (Kerlinger, 1986; Nunnally & Bernstein, 1994). Unfortunately, the gold standard does not appear to exist in the area of quality of life measurement. Predictive validity refers to the ability of the scores on the instrument to predict future outcomes. For discriminative purposes, validation focuses on cross-sectional construct validity, the extent to which the measure relates to other measures in a manner consistent with theoretically derived hypotheses about the concepts (Kirshner & Guyatt, 1985; Nunnally & Bernstein, 1994). For an evaluative measure, longitudinal construct validity is demonstrated when the within-subject changes in the measure after an intervention bears the expected relationship to changes in other variables measured (Kirshner & Guyatt, 1985). Although the intended use of many instruments is to evaluate outcomes in a clinical trial, validation of within-person change in an intervention study is rarely examined. Kirshner and Guyatt (1985) note that instruments with demonstrated discriminative ability are likely to be valid for measuring within-person change over time however, longitudinal examination of change is a more acceptable validation method.

From the viewpoint of the instrument purpose, it seems that QOL instruments have been advocated for use for each one of these applications. Cella (1992) notes three reasons to measure QOL: assess rehabilitation needs, evaluate treatment outcome and predict response to future treatment. The first two reasons can both be grouped as describing an evaluative measure, while the third basically denotes a predictive measure. In agreement with the evaluative point of view, Schipper and Levitt (1985) note that of primary significance is not a patient's quality of life measured at a point in time, but rather the pattern developed over time. In a discussion of the measurement of QOL in cancer patients, Hawthorn (1993) supports discriminative and evaluative applications for QOL measurement.

Within the area of QOL, much of the variation in measurement is the result of uneven scientific progress with regard to theory, measurement, and validity (Katz. 1987). There is a pressing need to expand research on clinical usefulness and credibility of QOL measures through validation by ascertaining if the relation between the variables measured is consistent with expectations based on theory (Schipper, 1983; Katz, 1987; Jones et al., 1987). Thus any validation of a measure concerns theory which should dictate the constructs that are to be measured and describe the properties of the resulting measures in terms of how constructs interrelate (Nunnally & Bernstein, 1994). One of the difficulties with the area of QOL measurement is that not all measures have documented validation, and if they do, the underlying theoretical framework is not clearly explicated (Gill & Feinstein, 1994).

Even if the contribution of theory is recognized in the assessment of validity, the question of how to evaluate validity of QOL instruments needs to be considered. The conceptual compartmentalization of content, criterion and construct "types" of validity is primarily a pedagogical device. Unfortunately, this can lead to a misinterpretation that "evidence" for any one type of validity may be sufficient to indicate the psychometric "soundness" of the instrument. This traditional view of validity does not supply any evidence in support of the inferences to be made; it "focuses on test forms rather than test scores, and instruments rather than measurements" (Messick, 1975, 1980). The consideration of the inferences made from test scores is particularly crucial when measuring a construct that is not directly observable, such as quality of life.

Validity is not a fixed characteristic of a test and cannot be proven but needs to be continually evaluated. Validity addresses the issue of the degree of confidence we have in the inferences that we make from the test and thus, the responsibility for valid use of a test also involves the person who interprets it (Cronbach, 1971; Streiner & Norman, 1989). Evidence for validity should focus on the justification for the inferences that are to be made from the test, during development of a new test or the application of an existing instrument in a new setting or with a different group of people (Streiner & Norman, 1989).

A more unified view of validity is that any evaluation of validity contributes to the construct validation of an instrument (Loevinger, 1957; Messick, 1980, 1989). Loevinger (1957) introduced a framework to evaluate validity within three components: the substantive component, the structural component, and the external component. The substantive component expands on the traditional view of content as an empirical evaluation of item relevance involving the analysis of response processes. This would involve the examination of the theoretical processes that the respondents engage in while attempting the assessment tasks, possibly using "think aloud" protocols (Messick, 1995). For example, the process representation of the construct of QOL for persons with a disability should be reflected in responses that consider the meaning of different life aspects with respect to satisfaction and importance and how their judgements of these life aspects affects and is affected by disablement. The structural component refers to the structural relations of items through evaluation of item or subscale interrelationships and scoring models. The scoring model should be consistent with what is known about the structural relations of the construct. For the construct of QOL, a theory that implies a relationship between satisfaction and importance for multiple dimensions would be consistent with a scoring rubric that used a weighting scheme and subscale scores. This rationale for the scoring model could then be evaluated empirically by comparing weighted and non-weighted scores and the determination of the dimension structure through factor analysis. The external component focuses on the patterns of relationships between similar and dissimilar measures of the construct, which is implicit in the theory of the construct being assessed. The constructs represented in the measure should account for the external patterns of correlations (Messick, 1995). Using the integrated model of disablement and QOL, the strongest relationships should be evident between QOL and constructs within the handicap level, such as community integration. This component approach to construct validity is broader than the view in which emphasis is placed on obtaining support for specific types of validity for specific purposes. Validity from the unified perspective focuses on the value of the assessment with respect to the inferences that are made from the test scores.

Another area of controversy surrounding QOL measurement involves the issue of generic versus disease specific instruments. The advantages and disadvantages of generic and specific instruments in assessing quality of life has received much attention (Aaronson, 1989; Guyatt et al., 1989; Patrick & Deyo, 1989; Williams & Wood-Dauphinee, 1989). The main strength of the generic instrument is that it is applicable to a wide variety of populations and thus allows comparison between interventions or conditions. The limitation is that the instrument may not focus on the aspects of QOL of specific interest and this could affect the ability of the tool to detect clinically meaningful change. Specific instruments on the other hand, have potentially increased responsiveness. Because specific instruments focus on a specific disease or population of patients, comparability across studies is difficult. Some of the practical considerations in choosing both types of measures includes: complexity of the questionnaire, ease and time to administer and scoring procedures. An alternative can be to use multiple measures particularly if it is determined that a single instrument will not yield all of the relevant information, or if the performance of different instruments is of interest. Although the scientific strength of the QOL assessment may be enhanced, there are potential problems with administration, complexity of statistical analyses and interpretation of results (Guyatt et al., 1989; Jalowiec, 1990). Of course the strategy chosen depends on the study objectives, methodological concerns and practical constraints. Regardless of the instrument chosen, demonstrated psychometric attributes are essential for any instrument to be useful.

Given the multidimensionality of QOL, aggregate scoring of a broad range of content areas becomes an issue. Is it appropriate to assume that combined scores for each area of content or domain will approximate a single index of QOL? This can lead to misinterpretation of results by assuming equivalence across dimensions (Cella, 1992). Since each life aspect can mean different things to different people, consideration of the relative importance of each of the items or major dimensions may help to clarify the inferences that can be made from the overall scores. The idea of measuring the importance of various elements has received support in the literature. Flanagan (1982) demonstrated that members of the general population differ in regard to the importance attached to various aspects of life. Pain et al. (1998) noted that among the focus groups of rehabilitation clients discussing the meaning of QOL, there was considerable commonality, but not all dimensions identified were important to all individuals or groups. In their critical appraisal of QOL instruments, Gill and Feinstein (1994) argued that " the quality of life may not be properly characterized unless patients are also invited to rate the importance of the problems".

Instruments can capture the value people place on different aspects in various ways. Flanagan (1978) formulated 15 categories representing five domains to measure the quality of life of a nationally representative cohort of American adults. Each participant was asked to respond using a 5-point scale to the question "At this time in your life, how important to you is...?" for each of the 15 factors. Cantril's self-anchoring scale (Cantril,1965) assesses an individual's sense of general well being. The respondent indicates where he/she describes his current situation by placing himself on the ladder (scale) which is anchored by the statements "best possible life" and "worst possible". In this way the respondent frames his own conceptions of "best" and "worst" taking into account what things are most important for them. The major drawback for this type of instrument is the inability to evaluate an individual's quality of life within the various dimensions said to influence one's assessment. Analyzing satisfaction of dimensions separately can help to indicate areas for intervention and the rating of importance can ensure a "client-centered" treatment focus. Laman and Lankhorst (1994) have developed a questionnaire to subjectively "weight" disability by measuring importance to evaluate the impact of various abilities. The purpose of the instrument is to identify the needs of individual patients and then plan an appropriate rehabilitation program. If the satisfaction and importance of life aspects is being evaluated in a measure of QOL, then it becomes important to assess the scoring model in an evaluation of validity which is addressed in the structural component of the framework proposed by Loevinger (1957).

The measurement of QOL is a complex issue. Instruments may be used to discriminate among participants at a point in time, predict future outcomes or measure changes after an intervention. Determination of psychometric properties within the constraints of an underlying theory is important. The choice of generic or specific measures, each with advantages and disadvantages, and the applied scoring will vary depending on the goals of the study. The consideration of all these issues is essential, but the concern with the inferences that can be made from the measurement should be paramount and this necessitates an ongoing evaluation of validity.

## Spinal Cord Injury Research

The rehabilitation outcomes for the spinal cord injured individual advocated by the various health care disciplines are most often objective and based on a model of disablement. Quality of life is becoming an outcome of great interest particularly when the individual has sustained an injury involving life long consequences. How is quality of life being studied? What consideration is given to definitions, theory or other guiding principles and the psychometric properties of the measurements? For the purposes of this evaluation, the literature review includes studies in which quality of life has been studied using the terms of life satisfaction and subjective well being.

Decker and Schulz (1985) were interested in how social support and perceived control correlated with life satisfaction and depression in middle aged and elderly persons with spinal cord injury. From the research in psychological adjustment the investigators used the theory of learned helplessness in which to guide their selection of the independent variables. They do not mention a theory or definition of the concept of life satisfaction, rather the discussion leads the reader to assume that adjustment and life satisfaction are synonymous. The Life Satisfaction Index - A (LSIA-A) was used to measure life satisfaction. This measure was originally developed and validated with healthy urban individuals aged 50-89 (Neugarten, 1961). Although not specific to SCI individuals, this measure would seem to be appropriate for this study given the age of the participants and reported reliability analysis was acceptable. A high degree of life satisfaction was most highly correlated with perceived control, quality and quantity of social support and perceived health. The first two factors are consistent with the theory of learned helplessness. Although perceived health contributes to the modified theory of disablement as outlined by Whiteneck (1994), the measurement of this item was limited to a single question about general health and more specific elements of impairment or disability could not be deduced from this information.

Other studies have used psychosocial adjustment literature as a foundation for the investigation of quality of life. In a sample of long term spinal cord injured individuals, Cushman and Hassett (1992) investigated the relationship between perceived quality of life and various factors of their current living situation. Variables evaluated included level of lesion, housing, marital status, employment, involvement in leisure activities and assistance required for activities of daily living. There did not appear to be a rationale or related theory that would explain the variables included in the investigator generated questionnaire. Concerning the variable quality of life, no definition was given and there was no information about reliability and validity of the measurement. Subjects were asked to rate their QOL on a 5-point scale using same age peers as a reference. In the analyses of results the sample was divided into two groups based on their perception of QOL in relation to their peers, worse or better/same. Level or completeness of lesion, which would be classified as impairment, was not significantly different between the two groups. Although the actual living situation was not much different for each group, whether or not it was the 'preferred' living arrangement was the significant factor pertaining to perceived quality of life. This finding was discussed as a possible reflection of social perception, which could certainly fit within the disablement model as a handicap.

With reference to the stage theory of adjustment, Stensman (1994) studied the relationship of medical, functional activity, psychological and social variables with quality of life. A theory of quality of life is not established and it is stated that the term "quality of life" cannot be distinctly defined. However, the author notes that for this study the concept of quality of life is understood to be influenced by several factors including psychological and physical conditions as well as relations to other people and society and that it is relative to the individual's perceptions. Without defining QOL or the factors that influence it, it made sense that the individual's subjective QOL was measured on a 0 – 10 point visual analogue scale. It does appear that the influential factors described are similar to the components of the Nagi and WHO disablement models. The addition of the individual's perceptions is in line with the outcome model of Whiteneck (1994). The results appear to support the proposed conceptualization of QOL. During interviews, subjects identified factors that they felt would raise their quality of life and these are consistent with the impairment and handicap levels of these models. The factors included: improved bladder function, less pain, the ability to drive a car, walking or moving better, and having a partner or children or both.

Two recent Swedish studies of individuals with SCI (Lundqvist et al., 1991; Siösteen et al., 1990a) analyze adjustment or adaptation to injury as it relates to community living activities and overall quality of life. Although they define the concept of quality of life as self-perceived overall quality of life, the problem lies in the choice of measurement tool. They have utilized the visual analogue scale in which participants indicate their answer to a question, "how would you rate your quality of life these days?". Visual analogue scales (VAS) have been shown to be sensitive and have been used successfully to measure QOL (Goodinson & Singleton, 1989; Padilla & Grant, 1985). One of the problems with this type of scale is that the level of abstraction required may be poorly understood by some respondents resulting in incomprehensible markings (Aaronson, 1989; Hawthorn, 1993). Usually, the VAS is a 10-centimeter line with anchor words or phrases at the extremes. In the case of these studies, using a 6-centimeter line numbered from 1 to 7 modified the VAS. This hybrid scale may create further confusion and reliability and validity is questioned. No significant difference for perceived quality of life regardless of physical capabilities was found, although this may reflect compromised responsiveness of the modified VAS. Factors related to higher QOL scores included access to private transport, degree of social activity and employment, elements that would be classified as disability or handicap. Only severe pain, an impairment classification, was shown to be related to lower QOL ratings.

Related to adjustment theory, a conceptual framework of coping effectiveness, the stress-transactional system, was used to guide a study on the relationship between coping and perceived quality of life (Nieves et al., 1991). In this study there was clear identification of how the selected variables related to the conceptual framework. Definitions were given for each of the variables, which provided a rationale for appropriateness of the selected measurement tools. However, the instrument used was validated for use with cancer patients and was modified for the study with no evidence of re-evaluation of reliability or validity. Although the results cannot prove causation, the information is useful in that it lends support to the conceptual framework, which can be used to enhance treatment strategies aimed at improving coping skills. The results of this study also support the model of the disablement process of Verbrugge and Jette (1994) which includes coping among the intraindividual factors that influence the main pathway.

Another common theme found in the literature was the examination of predictor variables to explore the contributions of specific life domains make to overall life satisfaction. The introduction to the article of Kinney and Coyle (1992) describes the neglect to include leisure activities in the study of quality of life of individuals with physical disabilities. There is no guiding theory and this may explain the multitude of measures, none of which specifically focus on leisure activities, used to identify the predictor variables. The terms life satisfaction and quality of life are used interchangeably and neither are defined adequately. A few years later, the results for the subsample of spinal cord injured individuals who participated in the above study, were published (Coyle et al., 1994). In this report, the difficulty in conceptualizing life satisfaction is explained by referring to social-cognition theories, suggesting that the critical element in understanding the lives of individuals with spinal cord injury is the individual's perceptions. Although the measurement of the predictor variables is explained in greater detail, the discussion of theory does not help to elucidate the rationale for selection of each variable. The dependent variable, life satisfaction, was assessed by asking the subjects the same question at the beginning and the end of the interview and averaging the responses, which were measured on a 7-point Likert scale. Leisure satisfaction was found to be the most significant predictor of life satisfaction and the discussion presents leisure activities as satisfying higher-order needs identified in Maslow's hierarchy of needs. The other significant predictors included self-esteem and health satisfaction. These predictors are also reflected in the intraindividual factors of lifestyle and psychosocial attributes as outlined in the model of Verbrugge and Jette (1994).

Krause and Dawis (1992) viewed the prediction of life satisfaction as important in understanding how psychological adjustment changes over time. The purpose of this longitudinal study was to identify the optimal predictors of life satisfaction using both demographic and adjustment variables as predictors. It appears the selection of the predictor variables was based on results of previous studies rather than theory. The predictor variables and the dependent variable, were both developed from the Life Situation Questionnaire (LSQ) a measure of mostly objective information and revised by the author to include several adjustment scales. Within this publication, no information is given regarding the validation of the revised measure. Although not cited in this study, limited statistical information for reliability and validity of the original scale are published elsewhere and recently the underlying dimensions have been analyzed (Krause, 1998a; Krause & Crewe, 1991).

The two scales used as outcome variables, general and economic satisfaction, were based on a factor analysis of 11 satisfaction items from the LSQ (Krause & Dawis, 1992). Some of the predictor variables were based on factor analysis of LSQ items and the other scales formed by combining items of similar content. When comparing concurrent and longitudinal predictors, the results showed that the variance accounted for by the concurrent predictors was greater for both economic and general satisfaction. For general satisfaction, health problems and dependency appeared in both concurrent and longitudinal analyses. Concurrent prediction also included emotional distress and positive affect, whereas longitudinal prediction added adjustment and activity. Included in both analyses of economic satisfaction were dependency and employment statuses. The demographic variables, age, time since injury and level of injury were unimportant predictors of life satisfaction. Although the results support the multifaceted nature of life satisfaction, inferences made regarding predicted outcomes are limited when discussed exclusive of guiding theory. It is interesting to note that in the conclusion the authors discuss the need to include environmental variables as predictors stating that , "basing the choice of these environmental predictors as well as measurement instruments on established theory would strengthen this type of research."

There have been a few studies that are concerned with the disablement process and the measurement of quality of life as a rehabilitation outcome. Using quality of life assessment to understand rehabilitation progress and program outcomes was the rationale for the study of Clayton and Chubon (1994). They discussed the necessity of an approach that went beyond objective indicators to include subjective measures that would get at the individuals' points of view. The development of the instrument used in this study, was based on the criticism that the impact of rehabilitation services needs to be assessed in a more comprehensive manner, the implication being the use of a model consistent with that of Whiteneck (1994). Reliability and validity data have been reported and a small sample of SCI individuals were included, however the author notes that findings are tentative due to reliance on convenience samples and other compromises in experimental rigor (Chubon, 1987). Education levels, employment status, income, social activities and severity of injury were found to be associated with perceived life quality. The association of lower QOL with greater severity of disability is contrary to other published studies (Cushman and Hassett, 1992; Fuhrer et al., 1992; Lundqvist et al., 1991; Siösteen et al., 1990a) however, this may reflect the discriminative ability of the measurement tool with similar groups of individuals with SCI. The authors state that this information is crucial to enhancing rehabilitation interventions aimed at promoting QOL, however the implications would be more valuable if interpreted with reference to the disablement process.

Fuhrer et al. (1992) have investigated the incorporation of subjective wellbeing as a rehabilitation outcome and the relationship of this concept to the ICIDH model of disablement. Subjective well-being, and its synonym, subjective quality of life, refer to the individual's global judgments of their life experiences and is a construct that subsumes component concepts such as life satisfaction, happiness and morale. They found that there was no relationship between life satisfaction, as measured with the LSIA and impairment (extent of lesion) or disability (functional independence). The participant's ages ranged from 19 to 77 years and although the LSIA was developed for use with the elderly, it was chosen to allow comparisons with the study of Schulz and Decker (1985). However, the reliability and validity of the LSIA has not been evaluated with individuals with SCI. Life satisfaction was significantly associated with three dimensions of handicap: social integration, occupation and mobility. In addition, Fuhrer (1994) reviewed the conceptualization, measurement and research findings of subjective quality of life in addressing the implications for this concept as a rehabilitation outcome. These papers make an important contribution to the understanding of the relationship between the disablement model components and subjective well being.

The evidence suggests that the study of quality of life as a rehabilitation outcome measure warrants important consideration, especially if the objective and subjective nature of the disablement process are to be understood. Unfortunately, the conceptualization of quality of life within a disablement model is not clear. This may be one reason why many of the studies lack theoretical reference and definition of the concepts. Perhaps it is the lack of a universally accepted theory or model that has resulted in the proliferation of different measurement instruments. This creates confusion regarding the application of the results and makes comparison across studies difficult. The objective concepts of disablement are crucial for evaluating the success of rehabilitation however, the current models need to be developed to include the subjective aspects of key concepts. This is not to say that measures of quality of life will replace traditional outcomes, but rather QOL would be measured as an additional effort to understand the consequences of disease and the impact on the whole person. The appropriateness of inferences made as a result of the measurement of QOL requires evidence of instrument validation with the population of interest.

## The Quality of Life Index

The Quality of Life Index (QLI) was developed in adherence to an individualistic ideology. The definition of QOL guiding the development of the measure focuses on the person's perspective of satisfaction with life aspects that are important to that individual. Originally, two versions of the QLI were developed, the generic version, meant to be applicable to all persons and a version for use with individuals undergoing hemodialysis treatment (Ferrans & Powers, 1985). Items for inclusion in these two versions were based on extensive literature review as well as a qualitative analysis of patient reports identifying the components of quality of life, and this resulted in the addition of three items to each section of the hemodialysis version (Ferrans & Powers, 1985).

A Likert-type 6-point scale ranging from "very satisfied" to "very dissatisfied" for part 1 and "very important" to "very unimportant" for part 2, is used for item response. Scores are calculated by weighting the satisfaction item with its corresponding importance item. The weighting of the scores could better reflect quality of life by including individual values as well as satisfaction. The rationale for the scoring scheme is based on the view that quality of life would be better for those who are satisfied with aspects of life they value and lower for those who are dissatisfied with valued aspects of life (Ferrans & Powers, 1985; Ferrans, 1996). Weighting is accomplished by centering the scale for satisfaction items on zero and then multiplying by the paired importance item. Adjustment of the satisfaction scores is necessary otherwise an individual with low satisfaction for an item of high importance would get the same score as someone with a high satisfaction for an item of low importance. By weighting importance, the highest scores are for items that have high satisfaction and high importance and the lowest for the items with low satisfaction and high importance. A total score can be calculated as well as subscores for the four domains with a possible range from 0 to 30.

Psychometric analysis of the original and hemodialysis versions revealed test-retest reliabilities within a one month period of 0.87 and 0.81 for graduate students (n=88) and patients undergoing hemodialysis (n=37) (Ferrans & Powers, 1985). Criterion related validity was also examined for these two groups by comparing the scores on the QLI with the measure of overall life satisfaction of Campbell and colleagues (1976), obtaining correlations of 0.75 and 0.65 respectively. Construct validation using factor analysis of the data from 349 patients undergoing hemodialysis treatment indicated that there were four dimensions underlying the QLI (Ferrans & Powers, 1992). The dimensions include: health and physical functioning, psychological/ spiritual, social and economic and family. Items within these dimensions cover the broad spectrum of components that have been included within other conceptualizations of quality of life as described previously. Construct validation was also supported by the contrasted groups approach in which those with a higher income had significantly higher QLI scores on the social and economic subscale (Ferrans & Powers, 1992). In addition, the internal consistency reliability was found to be very good with correlations ranging from 0.77 to 0.93 for the total QLI and the subscales. The QLI has also been adapted and shown to be reliable and valid with other patient populations (Bliley & Ferrans, 1993; Ferrans, 1990; Hicks et al., 1992; King, 1996; Oleson, 1990b). Other authors have noted that the QLI shows promise as a tool particularly because the measure not only reflects satisfaction but also the extent to which an individual values each life area (Goodinson & Singleton, 1989; Oleson, 1990a; Zhan, 1992).

### Summary

Conceptual clarity is important but difficult to establish in the area of QOL research particularly if subjective opinions of the individuals being studied are not considered. Instruments used to measure QOL ultimately define the construct for a given clinical or research situation. Therefore, it is important to examine the instruments themselves, their theoretical foundations, and evidence of validity to determine how well they capture the essence of QOL for a given patient population. Examining QOL of individuals with SCI should include the consideration of the disablement process as outlined by models such as the ICIDH (WHO, 1980). An integrated model of disablement that includes QOL would provide a better guiding framework. The fit between QOL and disablement is described differently by many authors, however the model of Verbrugge and Jette (1994) appears to be the most comprehensive and has been chosen to guide the validity assessement of the QLI with individuals with SCI.

Within the area of SCI research there seems to be a multitude of approaches to measure QOL. Unfortunately, most of the instruments applied have not been developed for use with this population and those purporting to be applicable to SCI individuals, lack conclusive, comprehensive evidence of reliability and validity. Alternatives for future QOL research may include the development of a new tool or the use of multiple validated measures to cover all the aspects of interest. Developing a new measure may not be feasible and the use of multiple measures with overlapping items may serve to irritate respondents. A preferred strategy may be to use a validated generic instrument with disease specific supplements. This is the approach that the developers of the Quality of Life Index (QLI) have taken when creating disease specific versions of the instrument. Although a SCI/Quadriplegia version has been created by the developers, there is yet no documented evidence of its psychometric properties with this population.

# III. Methods

## Purpose

The first purpose of this study was to evaluate the validity of the Ferrans and Powers Quality of Life Index (QLI) (Ferrans & Powers, 1985), with individuals with spinal cord injury. An application of the substantive, structural and external components of validity (Loevinger, 1957) is applied in the present study as it provides direction for the evaluation of instruments that measure a non-observable construct such as QOL. The second purpose involves the evaluation of possible predictors of QOL from prospectively gathered data. The theoretical framework that directs the objectives and hypotheses of this study is the disablement model of Verbrugge and Jette (1994). Although this model uses terminology based on the conceptualization of disablement proposed by Nagi (1965), the terminology of the ICIDH will be used as it is this model that has been widely accepted within rehabilitation in Canada. For this study, the author made the assumption that the reliability of the SCI version of the QLI would be similar to the estimates obtained during the original development of the QLI. Since there was potential for the results of this study to impact changes to the items and scoring of the QLI it was felt that the validity assessment should preceed the testing of reliability.

## Objectives

This study proceeded in three phases and the methods section will be organized according to each phase of the study.

Phase 1 – the two main objectives of this phase were to:

1. address the substantive component of validity by evaluating the response processes as an indication of item representativeness from the individual's perspective;
2. address the structural component of validity by:
   a) evaluating item interrelationships that are recognized by the participants as preliminary evidence of confirmation of the domains represented by the construct;
   b) evaluating the scoring model through examination of the relationships between the individual's ranking of the items in each domain and the corresponding weighted scores as well as the relationships between the weighted QLI total score and the non-weighted scores for the satisfaction and importance sections.

Phase 2 – the two objectives for this phase were to:

1. evaluate the external component by examining a priori hypotheses about the relationship between the QLI and other constructs represented within the theoretical model;
2. further evaluate the structural component by exploring the item interrelationships with a larger sample of individuals with spinal cord injury, independent from phase 1, using factor analysis.

Phase 3 – the objective for this phase was to:

1. determine the predictors of QOL from objective data gathered prospectively at one year after injury. At this point in time the measurements used as predictors were more likely to be stable and predictors of impairment, disability (functional limitation) and handicap (disability) could be identified.

**Hypotheses**

Phase 1

1. It was hypothesized that participants would confirm the representativeness of the items as contributing to overall QOL by the ability to cognitively interpret the item as "meaningful" in relation to their perceived quality of life.
2. a) In addition, it was hypothesized that the participants would recognize separate groupings of items, which would generally correspond to the domains of the QLI as postulated by the test developer, as well as provide support for the integrated theoretical framework of disablement and QOL.

   b) Also, moderately strong relationships would exist between the participant's ranking of the items per domain of the QLI and the weighted scores which would support the scoring model that incorporates a calculation of the satisfaction and importance component for each item. Furthermore, the relationships between the weighted QLI total score and the non-weighted satisfaction and importance section scores would be moderately high confirming the contribution of both the satisfaction and importance rating to the score.

Phase 2

1. The following are the a priori hypotheses about the expected correlations between the QLI and other constructs for the examination of the external component:

a) there will be no significant relationship between the QLI and the impairment level of the disablement model as measured by ASIA Total Motor Index Score (American Spinal Injury Association,1992).

b) There will be no significant relationship between the QLI and the disability level of the disablement process as measured by the Functional Independence Measure (FIM) (Keith et al., 1987).

c) There will be a significant negative correlation between the Reintegration to Normal Living Index (Wood-Dauphinee et al., 1988), a measure of the handicap level of the model, and the QLI and the degree of association is expected to be approximately -0.6.

d) There will be a significant positive relationship between the QLI and self esteem as measured by Rosenberg's self esteem scale (Rosenberg, 1965) and the degree of association is expected to be approximately 0.6. Self esteem is an intraindividual factor that can influence the main pathway of the disablement process.

e) There will be a significant negative relationship between QLI and locus of control as measured by Rotter's Internal-External (IE) scale (Rotter, 1966) and the degree of association is expected to be approximately -0.4. Locus of control is also an intraindividual factor that can influence the main pathway of the disablement process.

2. The factor structure will be similar to the four factor structure conceptualized by the developer of the QLI and the factors will be recognized as part of the integrated theory of disablement.

Phase 3

1. The strongest and statistically significant predictors of QOL will be those that indicate the handicap level of the disablement process.

## Phase 1

### *Sample*

A purposive convenience sample of eleven subjects was recruited for participation in this phase of the study. In qualitative studies, the selection of subjects is usually based on the inclusion criteria and the perceived usefulness of the information the subject may hold about the phenomenon under study (Shepard et al., 1993). In addition, sampling and analysis is an iterative process such that the sample size is determined when saturation is reached, no new additional information is being produced. Similar sample sizes have been used by Boswell et al (1998) (n=12) and Bach and McDaniel (1996) (n=14) in studies in which interviews were conducted to explore the meaning of QOL with persons with SCI. Individuals known to the investigator were contacted directly and others with whom the investigator did not have a familiar relationship were contacted either by a counselor at the Canadian Paraplegic Association or via an advertisement in the Association's newsletter. Prior to the commencement of the interviews, procedures were explained and all participants were required to sign a consent form (Appendix A). Within the context of this study, the validation was intended to determine if the measure was meaningful and accurately represented the perceptions of the persons with whom it was to be used. Therefore it was most important that the participants be able to articulate their thoughts and ideas. To broaden the discussion of experiences and opinions, it was also important that the participants were heterogeneous in terms of their spinal cord injury. Individuals with paraplegia and quadriplegia, male and female were invited to participate. Any individuals with concomitant head injury were not eligible to participate. The only additional criteria for inclusion was that the individual was at least one year post onset of SCI thus, likely to be stable in regard to adjustment to injury (Pilsecker, 1990; Richards, 1986) therefore less likely to become distressed when considering aspects of life quality.

### *Procedures*

### Objective 1 – Substantive Component

Participants answered the spinal cord injury version of the QLI (Appendix B) using a self-report interview format. The participants met with the investigator in a location of their choice, most often their home, to enhance comfort and ease of answering questions. At the meeting with each participant, demographic information was collected first (Appendix C) for the purpose of describing the sample characteristics. The individuals participated in a semi-structured interview in which they were asked to respond to each of the satisfaction items of the SCI version of the QLI. Prior to the interviews, the author added an item referring to the ability to have children, to the SCI version of the QLI in consultation with the instrument developer, creating a total of 36 items for each part. Participants only responded to the satisfaction items as the items for the importance section are the same, and it was felt that little additional information regarding item meaningfulness would be added. To assess the meaningfulness of the items of the QLI, participants were encouraged to "think aloud" and explore the thought processes they used to respond to each item.

The interview technique employed in this study was similar to the strategy outlined by Warnecke et al. (1996) who assessed the applicability of the QLI with culturally diverse populations. Considering the premise that attitudes are networks of interrelated beliefs that reside in long term memory, four cognitive tasks have been identified in the process of responding to questions (Strack & Martin, 1987; Sudman et al., 1996; Tourangeau & Rasinski, 1988). They are: 1) question interpretation/ comprehension, 2) information retrieval, 3) judgment formation, and 4) response editing. The first task essentially involves the respondent's understanding of the semantic meaning of the words and the pragmatic meaning, or the ability to infer the intent of the question. A problem at this level may be the first indication for question revision. The second task requires the respondent to retrieve a previously formed opinion or to access relevant information that will assist in the formation of an opinion. The ability to complete this task is influenced by the degree of importance of the issue and the degree of personal experience and is therefore related to the identification of the "meaningfulness" of an issue (Sudman et al., 1996). Forming a judgement often involves the respondent fitting responses to categorical alternatives, as in this study. Although the respondent's choice of a scale value and the frequency of these choices may depend on the range of the scale, the more the respondent has thought about a topic, the more readily the retrieved information is used when forming a judgement (Strack & Martin, 1987; Sudman et al., 1996). Again, this helps to confirm the item as meaningful from the individual's perspective. The response process is often a part of a social interaction between respondent and interviewer, and thus it is necessary to be aware of the potential effects of social desirability. This effect is usually limited to questions that may be viewed as threatening and could provide some indication that revisions are required. The evaluation of cognitive tasks as described in this study is to provide evidence that the respondent is processing the items in a way that is consistent with the QOL construct.

First the respondent was asked to answer each question by choosing a rating for the item using the 6-point bar graph scale with anchor phrases "not at all satisfied" at 1 (smallest bar) and "very satisfied" at 6 (largest bar). Response options also included: didn't understand question, refusal to answer or item not applicable. The bar graph scale and additional response options were modified from the original version of the QLI based on the work of Warnecke et al. (1996). Retrospective protocols through the use of standard probes or follow-up questions were used to explore comprehension, retrieval, judgment formation, and editing effects in the answer (Sudman et al., 1996). Respondents were asked to paraphrase a question or prompted to explain what they meant by their answer or how they went about answering the question according to a pre-established list of interview probes (Appendix D). Response delay or requests for clarification would prompt the investigator to repeat the probing question or rephrase the question to provide clarity. In addition, post-interview questions were used to ask respondents about the nature of the questions (which items would create discomfort/seem threatening and thus potentially lead to social desirability effects), the clarity and appropriateness of questions as well as suggestions for item addition or deletion.

### Objective 2 – Structural Component

To assess the domain and scoring procedures, each item from the QLI was printed on a separate 3 x 5 inch card. The cards were then spread out in no particular order, on a table in front of the individual. To assess item groupings (domains), each participant was instructed to "sort the cards based on how he/she thinks they should go together". They were told that there was no restriction on the number of groupings they could make and that there were no right or wrong answers. This exercise was to determine the categorization of the aspects of QOL from the participant's perspective, which would then be compared to the four domains of the QLI identified by the instrument developer.

For the evaluation of the scoring model, each participant was asked to rank order the items from each of the four domains that were printed on the cards. For this exercise, the cards with the items from each QLI domain were placed in front of the individual, one domain at a time, the item order consistent with the QLI. Each participant was instructed to order the cards in descending order, starting with the item that most "contributes to their determination of a good QOL" and ending with the item that least "contributes to their determination of a good QOL". The scoring model of the QLI is based on the conceptualization that the decision process in determining how each life aspect contributes to a good QOL is individual, involving the consideration of satisfaction with and importance of the life aspect. This exercise was intended to elucidate the decision process by evaluating the match between the item rank ordering by the participants and the corresponding satisfaction, importance and weighted scores (satisfaction times importance) for each QLI domain.

### *Analysis*

### **Objective 1**

Descriptive statistics were used to summarize the sociodemographic information collected and the responses to the QLI. Each interview was tape recorded and transcribed to provide the data for analysis of the QLI item relevance. In addition, notes written by the investigator regarding comments made by respondents after the tape recorded portion of the interview were also used to provide information for analysis. The transcripts of the interviews were analyzed qualitatively with particular emphasis placed on the words and phrases that provided an indication of the four cognitive tasks used in the response process. Careful review of each transcript determined if the participant was able to comprehend the question, retrieve relevant information and subsequently form a judgment about the item and then generate a response. The entire transcript for each respondent was reviewed at least twice, following which the transcripts were divided so that the responses to each item were analyzed separately.

Analysis of the potential problems associated with of each of these four tasks was based on the questionnaire appraisal coding system as described by Lessler and Forsyth (1996). Each item is evaluated and codes are selected from the appraisal system which describe characteristics that may affect response accuracy. The appraisal system is organized according to the four cognitive tasks of the response process and characteristics from more than one task may be recognized for a single item. With respect to the comprehension, it was important that the wording for each item evoke similar interpretation. During the interview process, minimal guidance was given to enhance comprehension, and only if the misunderstanding would affect the subsequent cognitive tasks. Comprehension problems may include difficulty with instruction clarity, complex or vague question structure, or mismatch between the question and answer. The information retrieved to form a judgement was expected to be somewhat different for each respondent in that life experiences would be individual, although some persons could describe similar events. Problems with the ability to describe or associate experiences in order to form a judgement for the item could indicate that the item did not provide "meaning" to their perception of QOL.

Modifications were made for items in which problem categories were recognized according to the appraisal coding system. Revisions were only considered if at least one third of the respondents had difficulty with any of the four cognitive tasks. Answers to post-interview questions regarding the items in the QLI were evaluated separately to determine if the majority of participants agreed regarding the clarity, and inclusion or exclusion of items. Revisions on the basis of the post-interview questions was made if at least one third of the participants agreed that the item was not clear, that an item should not be included or a new item should be added.

### Objective 2

The groupings of the items into "domains" by the participants were analyzed by comparison of the proportion of item pairings per domain by the respondent to the present four domains of the QLI using a four by four table. The proportional agreement of the respondents' item categorization with the actual item groupings within the domains was calculated. This analysis is meant to be similar to a confirmatory factor analysis to explore the interrelationships among the items as identified by the respondents and compare these to the factors or domains identified by the instrument developer.

To analyze the scoring procedures for the QLI, Pearson product moment correlations for each of the four domains were calculated between the individual's ranking of the items and the descending ranking of the weighted item scores (satisfaction times importance). In addition to the calculation of the weighted QLI score as per the developer's mathematical extrapolation, non-weighted scores were tabulated for the satisfaction section and the importance section separately. Pearson product moment correlations were then calculated between the weighted QLI score and the non-weighted satisfaction section score and importance section score.

## Phase 2

### *Sample*

For this phase of the study, individuals from the current member list of the Canadian Paraplegic Association (CPA) provided the sampling frame. The same inclusion criteria as outlined for the participants of Phase 1 was followed. Any participants from the first phase of the study were not eligible for the second phase of the study. Eligible subjects were initially mailed an information letter (Appendix E) describing the study and requesting their participation. If the mail recruitment method did not yield enough potential participants, contact by phone through a CPA counselor was the alternative recruitment method. To discuss the study, the principal investigator then contacted individuals that returned the response form. Those that expressed interest over the phone were then asked to arrange a convenient date and location for data collection. It was possible, that of the individuals who volunteered to participate, only those with a positive outlook may agree, which could have potentially affected results. Reason for nonparticipation was requested on the response form. To detect a product moment correlation of 0.4, the smallest hypothesized value, a sample of approximately 37 individuals were required to achieve power of 0.80 at a one tailed alpha level of 0.05 (Cohen, 1977). Although this calculation is based on values for interval data, sample size for ordinal data does not differ greatly for correlations of moderate size (Kraemer & Thiemann, 1987). To be more conservative to account for the use of ordinal data (a difference of 10 subjects for an expected correlation of 0.4) and to allow at least a 20% attrition rate without compromising desired power, the sample size estimate for this phase of the study was 55. To incorporate the factor analysis to evaluate the structural component, the estimated sample size required was 185 based on 5 subjects per variable (37 items) (Norman & Streiner, 1994).

### *Procedures*

### Objective 1 – External Component

The participants for this part of the study were required to undergo a physical examination and complete a number of questionnaires as set out in the hypotheses. To obtain accurate information and to ensure that respondents understood the nature of the tasks, the most suitable method of data collection was to conduct personal face to face evaluations as opposed to mailing out the surveys. To enhance compliance and improve the comfort level of the participants, the questionnaires were administered in the participant's location of choice, when possible. All participants were required to sign a consent form (Appendix F) prior to commencement of data collection. At the meeting with each participant, demographic information was collected first for the purpose of describing the sample and then a physical examination was conducted to determine the ASIA total motor score followed by the administration of the remaining questionnaires. If any of the participants could not read or write proficiently, the questions were read aloud and verbal responses were requested after which the investigator would circle the response.

### *Instruments*

The following data were collected from each participant for the examination of the external component:

Measurement of Quality of Life:

The SCI/Quadriplegic version (Appendix G), modified based on the results of Phase 1 of this study was used for this phase. Modifications included re-wording of some items to improve clarity as well as the addition of one item identified as relevant by the participants who were interviewed. The revised SCI version includes 37 items in each of 2 sections: one measuring satisfaction with various life aspects and the other measures the importance associated with those aspects. The psychometric properties of the original QLI have been discussed previously. Calculation of the scores by weighting importance results in a total score and scores for the four subscales that range from 0 to 30. A description of the scoring procedures can be found in Appendix H.

Other Measurements:

1) Level of Impairment. The standard neurological classification of spinal cord injury by the American Spinal Injury Association was used in this study (American Spinal Injury Association, 1992). These standards allow the determination of the motor and sensory levels through the evaluation of key muscle and sensory levels. For sensory evaluation, two aspects of sensation are examined (pin prick and light touch) in each of 28 dermatomes on the right and left sides of the body. Sensory appreciation is scored on a three point scale: 0=absent, 1=impaired, 2=normal. To determine motor function, key

muscles in 10 paired myotomes are tested. The strength of each muscle is graded on a 6 point scale ranging from 0, total paralysis to 5, normal active movement. Sensory and motor scores are then summed and this information is then used to determine classify patients with respect to the degree of impairment as represented by 5 distinct levels. The ASIA impairment scores are recommended for use in the analysis of rehabilitation outcomes (Lammertse & Yarkony, 1991). The ASIA total motor index score has been used in recent research which has examined the relationship of life satisfaction (Fuhrer et al., 1992) and social support (Rintala et al., 1994) with measures of impairment, disability and handicap. To facilitate comparison across studies and to simplify data collection, the total motor index score (Appendix I), which ranges from 0 to 100, was used in this study as the measure of paralytic impairment.

2) Degree of Disability. Evaluation of functional status was done by using a self-report version of the Functional Independence Measure (FIM) (Keith et al., 1987) (Appendix J). The FIM is comprehensive measure of disability that has been frequently used clinically and in research with various patient groups. The goal in developing the FIM was to devise a tool useful in treatment and program evaluation, quality assurance, determining cost effectiveness and policy decision making (Heinemann, 1991). The conceptual basis of the FIM is the estimation of burden of care through the evaluation of self care, sphincter control, mobility, locomotion, communication and social cognition (Hamilton et al., 1987). Each participant's degree of functional independence is assessed on a 7-point Likert scale, 1 indicates "total assistance" required and 7 represents "complete independence." A total score is derived from the sum of ratings across all 18 activities, possible scores range from 18 to 126, the higher score indicating greater independence. Although the FIM includes measurement of comprehension, expression, social interaction, problem solving and memory, these items were not assessed as a part of this study as it was the aspect of physical functioning as measured by the motor subscale, that was of interest. Thus only 13 items were assessed and the possible score ranged from 13 to 91.

Evaluation of the seven level FIM has revealed consistently good interrater reliability results for each of the items of assessment, with intraclass correlation coefficients ranging from 0.88 to 0.93 (Hamilton et al., 1991). Predictive validity has been examined in a sample of stroke patients (Wilson et al., 1991), in which both admission and discharge FIM scores were found to be strong predictors of the likelihood of return home. Examination of the overall FIM and the motor and cognitive subscales using Cronbach's alpha has produced results ranging from 0.86 to 0.97, indicating high internal consistency (Dodds et al., 1993; Stineman et al., 1996). The FIM has also been shown to be responsive to changes in function and possess adequate discriminant validity (Dodds et al., 1993).

Two studies have examined the relationship between functional independence and life satisfaction (a synonym of QOL) for persons with spinal cord injury. Dunnum (1990) found a correlation of 0.65 between the overall score of the Life Satisfaction in the Elderly Scale(LSES) and the Barthel Index. The correlation was reported as not statistically significant, although this may be a typographical error as the sample size for this study was 31. The participants ranged in age from 18 to 78 years (mean = 35 years), and one of the limitations cited includes the lack of reliability and validity information of the LSES when used with persons under the age of 55 years. The Life Satisfaction Index-A (LSI-A) and the self report version of the FIM were used in the study of Fuhrer and colleagues (1992) to evaluate the relationship between life satisfaction and measures of impairment, disability and handicap.

3) Degree of Handicap. The Reintegration to Normal Living index (RNL) (Appendix K), a self-report questionnaire designed to assess global function (Wood-Dauphinee & Williams, 1987) was used to measure various dimensions of handicap. The measure was designed to assess global function and considers the patient's perceptions of their own capabilities and the objective indicators of physical, social and psychological performance. The RNL evaluates eight areas related to activity and daily living and three areas related to self perception. Each statement of the 11 item index is scored using a 10 centimetre visual analogue scale (VAS) which is anchored by phrases that require the patient to determine whether or not the statement describes their situation (Wood-Dauphinee et al., 1988). The score for the 11 items ranges from 0 to 110, but is proportionally adjusted so the maximum score is 100. The evaluation of internal consistency, inter-rater agreement, responsiveness, content, criterion and construct

validity using three separate samples of patients is well documented and demonstrates promising results (Wood-Dauphinee et al., 1988).

The only study that has specifically examined the relationship between life satisfaction and handicap in individuals with SCI (Fuhrer et al., 1992), used the Craig Handicap and Assessment Reporting Technique (CHART) as described by Whiteneck et al. (1992). Although the CHART assesses five of the six dimensions of handicap as outlined by the World Health Organization, Fuhrer et al. (1992) chose to measure only three: social integration, occupation and mobility. These dimensions are also included in the RNL, which has been used as a measure of handicap in a longitudinal follow-up study of patients with spinal cord injury (Daverat et al., 1995).

4) Self Esteem. Self esteem was measured with Rosenberg's Self Esteem Scale (RSES) (Rosenberg, 1989). Self esteem, refers to the beliefs one has about oneself in terms of respect and worth, which involves the consideration of both positive and negative attitudes. Sources of self esteem include internal factors, the degree to which an individual likes himself and outside sources such as social factors, achievements and physical appearance. The experience of sustaining a spinal cord injury results in an "experiential split" where the individual views the internal concept of self as being the same as prior to the injury, but the external sources of self esteem have changed thus requiring an individual to "rediscover" the self (Carpenter, 1994).

Rosenberg's Self Esteem Scale is composed of 10 statements in which one of four choices is selected. Respondents may answer "strongly agree", "agree", "disagree" , or "strongly disagree" to statements such as, " On the whole, I am satisfied with myself." The answer is then reduced to either a positive or negative score (positive responses indicate low self esteem). A positive or negative score is determined for six scale items since some scale items combine the answers to more than one statement. Some authors (Coyle et al., 1994; Kinney & Coyle, 1992; Piazza et al., 1991) have described and used the RSES as a Likert or Likert-type scale in research of individuals with SCI. For each statement, the four response choices would be presented with the choice representing high self esteem as number four. Therefore, the scores would range between 10 and 40 with a higher score indicating a higher level of self esteem. This version would require that the choices would not remain consistent, 1=strongly agree and 4=strongly disagree, as is the case with the original measure. Rosenberg (1979) reported a coefficient of reproducibility of 92% and a coefficient of scalability of 72% for the original scale. In a study involving spinal cord injured participants (Coyle et al., 1994), examination of internal consistency generated a Cronbach's alpha value of 0.85. For comparability with the results of other studies involving individuals with SCI, the RSES will be used and scored as a Likert scale (Appendix L) for this research.

In the area of SCI research, self esteem has been studied in relation to a number of variables. Comparison of levels of control, self esteem and coping for individuals with SCI and a matched control group, revealed lower levels of self esteem for the SCI cohort during the first year post-injury, although the mean values for scores on the RSES did not indicate low levels of self esteem (Hancock et al., 1993). The authors feel that these findings indicate that therapy and support could be enhanced to maximize adjustment and thus quality of life. Also using the RSES, Piazza et al. (1991) found a statistically significant relationship between hope and self esteem and that self esteem was the best predictor of hope for SCI individuals involved in active rehabilitation. In a study predicting life satisfaction among adults with spinal cord injury (Coyle et al., 1994), leisure satisfaction was the most significant predictor followed by self esteem as measured by the RSES. Since these studies with SCI individuals have utilized the RSES, it will be possible to make comparisons with the scores obtained in this study.

5) Locus of Control. For this study, locus of control was measured with Rotter's Internal-External (IE) scale (Appendix M) (Rotter, 1966). The conceptual basis for this scale views persons believing they have high degree of control over life events as having an internal locus of control, and those believing they have little personal control as having an external locus of control. This is a forced-choice 29-item scale, which includes six distracter items, and is scored by totaling the number of externally oriented responses checked. The scores can range from 0 to 23, the higher the score the more externally oriented the individual. Correlations ranging from 0.65 to 0.79 are reported for the examination of internal consistency and the test-retest reliability (0.60-0.83) for a one month period are consistently acceptable (Rotter, 1966). In addition, discriminant validity was indicated by low relationships with variables of intelligence and social desirability.

Locus of control has been examined within the spinal cord injury population with specific emphasis on the relationship between this construct and coping, most often inferred from measures of depression. Using Rotter's IE scale, Ferington (1986) studied the relationship between personal control and coping effectiveness as determined by the Beck Depression Inventory. A positive relationship was found (r=0.23) supporting the hypothesis that a low IE score (greater internal locus of control) is associated with lower depression scores. A measure derived from the conceptual basis described by Rotter (1966), but focuses on health related beliefs, the Multidimensional Health Locus of Control scale (Wallston et al., 1978), was used in a study involving 53 SCI patients in active rehabilitation. In this study, (Frank & Elliot, 1989) found that individuals with internal attributions of health control had significantly lower depression scores than those who believed in chance. Perceived control (a measure developed by the authors, the higher score indicating greater control) has also been shown to correlate (0.52) with life satisfaction in a sample of individuals with spinal cord injury over 40 years of age (Decker & Schulz, 1985).

### Objective 2 – Structural Component

The data for this phase of the study were collected during the visits with the investigator as described under the heading of the first objective. The participants' answers to the QLI questionnaire (as modified from Phase 1) were used to evaluate the structure of the QLI for this second objective.

### *Analyses*

### Objective 1

Descriptive statistics were used to summarize the sociodemographic information of the sample and the data collected with each of the instruments used in this phase of the study. Analysis of variance and t-test of Pearson's r were used to examine the influence of the demographic variables on quality of life.

Correlations between the QLI and each of the other measures were calculated. The data were treated as interval level data and thus the appropriate statistic to determine the degree of association was the Pearson's correlation coefficient. The level of significance of the correlation was analyzed using the t-test with an alpha level set at

0.05. Each of the calculated correlation coefficients was compared with the a priori hypotheses to determine if the theoretically expected associations existed.

**Objective 2**

To determine the factor structure of the SCI version of the QLI, an exploratory factor analysis was applied to the data. Principal components analysis was the extraction method used to identify the simple factor structure for the data. From this analysis the decision rules used to identify and determine the number of factors that best fit the data were Kaiser's Criterion and Cattell's Scree Test. Image factor analysis with varimax rotation was the third criterion used to determine the simple factor structure. These analyses were followed by principal factor analysis with oblimin rotation to produce an oblique factor solution. The factor solutions were analyzed according to the following criteria: retaining the items for each factor if they show a loading of 0.4 or greater, examining the number of items that did not load on a factor and examining the factorial complexity, the number of items that loaded on more than one factor. In addition, the resulting factors were compared descriptively to the integrated theoretical framework of disablement and QOL.

**Phase 3**

***Sample***

Individuals that participated in Phase 2 of this study were included in the third phase if they were also included in the prospectively gathered longitudinal data base of 833 consecutive spinal trauma victims admitted to the University of Alberta Hospital between 1983 and 1991 (Reid et al., 1992). Permission was given to access the data library from the Alberta Spine Trauma Study Group (Appendix N). Generally, for predictive studies it is desirable to have a sample size that is at least five times the number of predictor variables. As this study will use five predictor variables, the sample size required is 25 (Norman & Streiner, 1994), however to improve power the estimated sample size was adjusted to 50 subjects. In the event that there were not enough subjects from Phase 2 that were identified to be part of Phase 3, additional subjects were recruited by mailing requests for participation (Appendix O) and a consent form (Appendix P) through the CPA to individuals injured between 1983 and 1991.

### *Procedures*

The design for this phase of the study most closely resembles prospective non-concurrent. The predictor variables have been collected prospectively since 1983. The criterion measure of QOL, the modified QLI, was measured in the present as part of phase 2 of this study. Additional subjects were sent the QLI through the mail and returned the demographic data sheet, the QLI questionnaire, contact information and the consent form to the investigator. If there were any problems with the completeness of the data, the investigator contacted the individual by phone to get further clarification. The predictor variables selected from the year one post-injury data of the database represent the categories of impairment, disability and handicap as defined in the model of the disablement process. The following measures were used as predictor variables:

1) Pain is a variable that represents the impairment level. Pain was recorded a yes/no response to the question "Do you have pain from your neck or back injury?"

2) Also representing the impairment level of the disablement process, is the level of injury measured with the ASIA total motor index score. Details for this measurement have been discussed previously in Phase 2 as part of the instrumentation section.

3) The disability level variable is the score for the items of physical functioning of the Functional Independence Measure (FIM) which has also been discussed in detail in Phase 2. The items of comprehension, expression, social interaction, problem solving and memory were not included, as there was no variance among the scores for these items in the database.

4) Also representing the disability level is a variable that describes walking. The walking variable was derived from categorization of the original four level ordinal variable. A score of 1 was given if the database file response indicated that the subject did not walk at all or only walked for exercise; a score of 2 was given if the database file response indicated that the subject was a functional walker, with or without aids.

5) The handicap level variable of employment was categorized as yes/no. Employed persons were those who, during the reference week: a) did any work at all; b) had a job but were unable to work due to personal or family responsibility, bad weather, labor dispute, vacation, or another reason. Unemployed persons were those who, during the reference week: a) were without work, had actively looked for work in the past 4

weeks and were available for work; b) had not actively looked for work in the past 4 weeks but had been on a layoff and were available for work; c) had not actively looked for work in the past 4 weeks.

### *Analyses*

Descriptive statistics were used to summarize the sample characteristics and the data for each variable. Analysis of variance and t-test of Pearson's r were used to examine the influence of the demographic variables on quality of life. Univariate correlational analyses were used to determine which potential predictor variables to enter into the regression analysis. The QLI and two of the predictor variables, the FIM and the ASIA motor score were treated as interval level data and therefore described using Pearson's r and analyzed for statistical significance using the t-test of r. Employment, pain, and walking status were all measured at a nominal level and when evaluating the relationship between interval and nominal variables, the statistic used is Eta. Linear Regression analysis with forced entry was used to determine the amount of variance in quality of life that was explained by the predictor variables that were significant ($p<0.05$) at the univariate level.

## Ethical Considerations

Ethics approval from the Health Research Ethics Board was received prior to commencement of the study. All participants were required to sign a consent form prior to data collection, and a copy was given to them. Care was taken to ensure that each participant understood the issue of confidentiality, voluntary participation and withdrawal from the study at any time. There was the chance that some participants may experience psychological distress as a result of examining their life situation so thoroughly. The investigator tried to provide a comforting experience by having the interviews take place in a location of the participant's choice. If it was noted that the participant was experiencing any distress, information regarding counseling was offered to them. Only one measurement required any physical exertion on the part of the participant. The muscle testing procedure involved is an integral part of rehabilitation and thus each participant had experienced this type of testing. There was still the potential for muscle soreness or fatigue so the number of repetitions for each muscle was kept to a minimum.

# IV. Results

## Phase 1

The sample for this phase of the study consisted of eleven participants, of which there were six individuals that had a familiar (client-therapist) relationship with the investigator. The characteristics of the nine males and two females that agreed to participate are presented in Table 4-1. The participants ages ranged from 26 to 42 years (mean=33.1, sd=5.24). Eight individuals had a spinal cord injury that resulted in complete quadriplegia and the other three participants had thoracic level injuries resulting in complete paraplegia. All individuals were wheelchair dependent and only two were married at the time of the interviews. The average duration of injury was 10.5 years, ranging from 1.6 to 26.8 years. Only two of the participants were employed and one was attending school. More than half of the participants had completed some level of post secondary education. The average age, duration of injury and educational status of the participants in this study are similar to those documented in other studies of QOL for individuals with SCI (Clayton & Chubon, 1994; Fuhrer et al., 1992).

## Objective 1 – Substantive Component

The first objective focused on the evaluation of four tasks of the response process as an indication of item representativeness. Analysis of the participant interviews with respect to each item revealed that when difficulty occurred, it usually involved the first of the four tasks, question interpretation/ comprehension. During the interviews various re-wordings suggested by both the investigator and participant were explored so that any modifications made would include participant feedback. When possible, rewording was tested with subsequent participants after the original wording was read, and considered when determining revision of an item. Educational level was unlikely to have influenced the participant's ability to understand the questions as most had at least a high school diploma. It was not the intent of this study to evaluate the ability of individuals with low levels of education to understand and interpret the item meaning. Identified problems are reported for the items according to the four cognitive tasks of the response process. In addition, part of the evaluation of the substantive component involves the consideration of the theoretical framework and how it is represented in the response process.

**Table 4-1.** Participant Characteristics – Phase 1

| Duration of Injury (years) | Age | Gender | Level of Injury | Employment Status | Education Status | Marital Status | Dwelling |
|---|---|---|---|---|---|---|---|
| 1.6 | 32 | M | C 5 | U | HS | divorced | Apartment – rent |
| 3.1 | 35 | F | T 12 | U | PS | married | House – own |
| 5.2 | 26 | M | C 6 | U | PS - I | single | House – Parent's |
| 7.7 | 31 | M | C 6 | E | PS | separated | House – own |
| 8.1 | 32 | M | C 6 | U | PS - I | single | Apartment – rent |
| 8.9 | 26 | M | T 5 | U | HS | single | House – rent |
| 9.1 | 37 | M | C 7 | U | T | single | House – own |
| 9.9 | 28 | M | C 4 | S | PS - I | single | Apartment – rent |
| 14.8 | 39 | M | T 11 | U | HS -I | single | House – own |
| 20.3 | 36 | M | C 6 | E | PS | single | Apartment – rent |
| 26.8 | 42 | F | C 6 | U | HS -I | married | House – own |

Abbreviations:
M – male; F – female; C – cervical; T – thoracic; U – unemployed; S – school; E – employed: HS – high school; PS – post secondary; T – trades certificate; I – incomplete.

### Interpretation/ Comprehension

For the item "ability to clear secretions from you lungs", responses to the probe asking what was meant by secretions indicated a possible problem category that interfered with question comprehension. The technical term "secretions" was not readily understood by all as evident by comments asking what secretions were or trying to equate the term with another that they understood. Although some participants responded to the probe by describing their ability to cough, the re-wording of the question needed to explore more than just coughing ability. Some individuals described an ability to cough, although with difficulty, but with the interpretation probe they considered their ability to get "phlegm up" or "get things out and get things up". With a spinal cord injury, the ability to cough needs to be considered in combination with the ability to clear the lungs, as there is the potential for developing medical complications. Participant comments echoed the same concerns: "If I'm on my own, and God forbid I aspirated or something went down, I'm in trouble"; "it's a little harder, I have to brace myself and help it along by squishing my stomach"; "I have to watch because I'm susceptible to pneumonia and it's very frustrating when you can't cough it up". Therefore, the revised form of the question "How satisfied are you with your ability to clear your lungs" enabled participants to interpret the question without difficulty and consider the item as it was intended.

The item that referred to the amount of pain that they have was considered for modification due to a comprehension problem, but was then left as originally worded. It was apparent that when participants answered too quickly, e.g. they selected a rating from 1 to 6, the problem category identified was a question/ answer mismatch. This was not a problem for individuals that had pain, as they readily recognized that a rating of 1 or 2 meant they were dissatisfied with the amount of pain that they have. Two participants with little or no pain did not understand which end of the scale they should choose and required some prompting or re-reading of the question, however three other individuals without pain did not have the same difficulty. This was evident by comments such as: "I basically don't have pain so I guess I would be very satisfied"; "Five, because I hardly have any pain at all"; "Probably a five, I don't have much pain". It was felt that any modifications to the question would make it more complex and removing the word "amount" was not considered an option. Without reference to an amount, many individuals would likely choose the "not applicable" response, potentially resulting in missing data about the range of pain perceived by individuals with SCI. Participants with little pain felt they couldn't answer if asked "How satisfied are you with the pain you have". They felt the question would then be directed to persons that have pain most of the time and would likely have pain at the time of the interview. The inclusion of the word "amount" prompted them to consider that even little or no pain was an amount and therefore consider an answer.

Question interpretation, which impacted information retrieval, was the problem evident with the original item "How satisfied are you with your faith in God?" With respect to comprehension the problem was categorized as an implicit assumption that faith in God did not include alternative views such as a higher power or spirit. If their faith or beliefs did not include God, the participants dismissed the item as not applicable. For those that stated they did not believe in God, there was no detailed reference for information for which they could form a judgement. When asked if they had some type of faith or belief in a "higher power", many were then able to comment on the beliefs they had and discussed a level of satisfaction or dissatisfaction with those beliefs. The question required revision to focus the participant on their beliefs without reference to a specific deity. The item was revised to read "How satisfied are you with your faith, whatever that means to you?"

### Information Retrieval

Information recall or retrieval was the issue with the item "How satisfied are you with your chances of living to the age you would like?" All the participants comprehended that the item referred to getting older, but results from the probe that required information retrieval indicated problems with this item. As the participants thought out loud when answering this question, many felt they had no information on which to base a judgement since they had not really thought about what age they wanted to live to. Further probing resulted in participants expressing their concerns in terms of the length of their lives rather than a specific age. For example: "realistically, I can say that I won't live as long with this injury as I would of able bodied"; "as long as you look after yourself, you can live to be fairly old if you want to be"; "normal life expectancy";

or "I don't believe I will live as long as I would now as I would of before my accident". They were then able to consider their situation in terms of limitations of living longer due to the physical consequences of spinal cord injury, or wanting to be around for significant events in their children's lives. Improving this item involved the removal of the reference to age and the question was revised to "How satisfied are you with your chances of living as long as you would like?" Based on the comments made by participants, it was felt that this would help individuals to think of events associated with growing older rather than deciding on an age they would like to reach.

The need for an additional item was based on the interview results with the first two participants, each of whom did not have a significant other in their life at the time of the interview. When asked "How satisfied are you with your spouse, lover or partner?", comprehension was not a problem and the immediate response was "not applicable". Further discussion revealed that having someone in their life was in fact quite important to them and they felt this would enhance the quality of their lives. One participant stated "I think the only thing that could really enhance my future is to get a soul mate, somebody that I can really love". It appeared that the problem category related to the retrieval of information, as the participants would be required to shift the reference period used to evaluate this question to a time when they were involved in a relationship or to think of the future. This was not recognized as an option but rather the fact that they currently did not have a significant other meant they were unable to answer the question. It became evident that meaningful insight may be obtained by accessing information about "not having a significant other". In subsequent interviews, if a participant answered not applicable to the item about having a significant other, then an additional question, "How satisfied are you with *not having* a spouse, lover or partner?" was asked. Participants then recalled events concerning relationships they had in the past and would discuss what they missed and would like to have again. Based on the reports of these participants, it was decided that the item should be added with qualifiers in brackets (if you have/ do not have) similar to the items regarding employment.

For the participants that were single, there was the potential for problems with information retrieval for the item regarding "family responsibilities" as it was anticipated that the interpretation of family would focus on spouse and children. This was not apparent by the answers as some individuals immediately referred to parents or siblings and would discuss different aspects of their responsibilities toward those individuals. This is likely because of the placement of this item within the questionnaire. Previous items had asked the participants to discuss aspects concerning family and they identified who those people were to answer those questions. Information retrieval for some items was noted to be similarly consistent among the participants. For example, the item regarding "friends" indicated that almost all individuals recalled situations involving friends that have stood by them since their spinal cord injury and it was this evaluation of loyalty that was used to form their response to the question.

### Judgement Formation

Problems with this task can arise when the response requirements, in this case there was the choice of 6 categories, are not congruent with the recalled information. In this study participants did not appear to have any difficulty choosing one of the six response categories. The only difficulty that may be related to this task was the difficulty participants had when deciding which end of the scale to choose, specifically for the items that asked them to consider an amount as in the item about "worries". In formatting the response, the participants would verbally question themselves. For example "amount of worries in my life, oh I guess I'm pretty satisfied, I don't really worry that much, I'd say a six" or "satisfied with the amount of worries? Like as in, if being unsatisfied if I have a whole bunch of worries? I'd say a four". When the question required retrieval of information related to ability there was usually no difficulty in formatting a response. As expected, for the items that referred to abilities that the participant had more experience with, the judgement formation was more immediate.

### Response Editing

During the interview there was no evidence of problems with response editing, specifically participants were still able to discuss information of a sensitive nature and did not appear to word their responses in consideration of what is socially acceptable. Individuals spoke of both positive and negative aspects relating to each item. In one instance, the participant was forthright regarding his negative opinions of his health care despite the fact that the researcher represented the health care profession. The lack of response editing could also be a function of the comfort level felt by the participant because the interviewer was someone with a personal connection to an individual with SCI. This issue of interviewer – participant familiarity was addressed in the post interview questions.

### Added Item

The item pertaining to the "ability to have children" added to the QLI prior to the interviews, was found to be acceptable based on the discussions that followed the interview probes. There were varying levels of knowledge regarding this aspect of their lives. Numerous comments indicated that they had considered their ability to have children in light of their spinal cord injury. "It's definitely something in the back of my mind, they say it's possible"; "I really can't have children"; "Physically, I can't without help". There was a clear understanding that the ability to have children is different after spinal cord injury. In general there was knowledge of "all the techniques they have and the processes that need to be done". Some individuals were uncertain about their own physical capabilities, and some participants described second hand knowledge, either referring to friends that have tried to have children or describing the situation for individuals with spinal cord injury in general. It appeared that their judgements were based on this general knowledge and the experiences of others. The prospect of having children after spinal cord injury elicited much emotion. This was evident by the following comments, " I would have figured my having children was completely out of the question but apparently it isn't so, I'm kind of happy about that but it's got some pretty complicated processes and I'm not really too happy about that"; "Well, it makes a guy feel lousy but I've sort of got used to the idea"; "I'd love to have a couple of kids, that can't happen so I'm not very satisfied with that"; and "it's very depressing... and then it is too much strain on the relationship (with your spouse)". The comments by the participants confirmed the relevance of this issue for individuals with spinal cord injury and thus provided support for the inclusion of this item.

### Post-Interview Questions

The post-interview probes revealed that the areas covered in the QLI met the expectations of the individuals interviewed. When asked if there was anything that was not covered that was important to their quality of life, most felt that the questionnaire was very complete as indicated by general comments such as, "I don't think you've really missed anything"; I think you've covered the bases good" and " I think you've covered pretty much everything". One individual elaborated by saying "you pretty well covered how I feel, and family, and education and job wise and how I feel about myself, how much I can actually do for myself, so I don't think there's much other than that".

However there were some aspects that participants felt were not covered. One individual brought up the issue of residential aides, although he was not specifically thinking about himself. He stated that "I think maybe getting into specific, uh, people who help them...I know people who live here, who employ people and they don't have any choice and they're very unhappy". A review of the interviews indicated that 6 out of the 8 persons with quadriplegia, including the individual who mentioned the addition of this topic, discussed the aspect of personal care via an attendant, aide or homecare in two of the QLI items. When discussing item 2 about the health care they were receiving, individuals commented on how they felt about their aides. For example, "home care, they're very good and then my own workers that I hire, I get to pick and chose which ones work for me"; "my full time (aide) is great, but some of the part time people...some little things with transfers, technical things...I am very satisfied with how I'm being helped right now"; "My new health care worker, I don't think he has too much knowledge with spinal cord injuries and doesn't realize that it's a disability not a disease...it's just a learning curve for him I guess". In addition these same eight individuals discussed the help they receive from their aides when answering item 5 about the ability to take care of themselves without help. In this item the discussion focused on the tasks that they needed help with and many comments were similar such as "I need everything from my food cut to my routines in the morning, there's really not a heck of a lot I can do"; "helping me with everything, like bathing and dressing and the whole bit"; "I can't do my personal care by myself ...I need someone to cut up my food, but I can feed myself". Given the similarity of events recalled by these participants regarding the aspect of attendant care, it does not appear that a separate item would be warranted.

Another issue that was discussed for inclusion was the aspect of a vacation. This topic was only mentioned by a few of the participants when answering the item about the things they do for fun and only in general terms. There would be reference to "going places" or "going to the beach" or "going on holidays". However, reference to vacation also came out in other items such as the item pertaining to achievement of personal goals in which the individual stated "that's my main goal, to take my kids to Disneyland and then to do my own travelling once they've grown". Vacation was also associated with the item pertaining to financial needs when one participant stated that (with the money he has) "you definitely can't go on a vacation for two weeks, that's for sure". As the topic was considered, although not by all participants, it was determined that it was not necessary to include a separate item.

One participant indicated that the issue of stress was not really covered in the item asking about worries because "there are things that people worry about, like somebody might worry that, oh I don't know, somebody's plane is okay, but stress might be more of a constant thing." Only two participants specifically referred to stress when answering the item about the amount of worries in their life. Despite this, the majority of participants' responses were very detailed, describing various situations including events that had occurred or may occur with their children or family, their financial situation with respect to their needs as a person with a disability, or their physical disability and how it may affect their job potential or their health. Given the detailed description of the participants' worries, it was not necessary to change the wording of the item to include stress.

Another participant discussed an issue that concerned accessibility to events, which had not been considered when answering the item about the ability to go places outside their home. It became clear that the participant was not referring to the physical access. "I still go to them…these places are all completely accessible for me, it's the inconvenience that I have to go through because you're in a wheelchair and you're only allowed to sit in a certain spot. I should be able to sit anywhere, I can transfer into any seat…but they want to put me in the back row, with one escort." It appeared the point being made was the fact that these guidelines discriminated against persons with disabilities and the participant expressed a lack of control for these situations and that changes should be made. "There are more and more of us, and you know, it should be recognized." Comments made by other participants when answering the item about control over their lives reflected similar sentiments. Some statements were general, "being able to do what you want, when you want"; "do what I want to do instead of having other people and situations dictate that to me"; "basically what I want to do and nobody's saying no or nobody's stopping me". Other comments were directed at specific situations, "with home care, I pretty well have to abide by their rules"; "if you go through government funding, you never know what that's going to be"; "dealing with the health care, they tend to make you feel like, you can lose control". The situations discussed, whether in general or great detail represented the issue of control and another item was not necessary.

The discussion of the items did reflect the theoretical framework of the disablement process. The participants considered aspects of their lives from all levels of the main pathway. For example, the impairment level was considered when discussing health and health care issues such as skin breakdown, bowel and bladder function and when discussing personal appearance, the issues of muscle strength and skeletal deformity were mentioned. The disability level was emphasized in many items when participants considered their specific abilities in terms of personal care and daily activities. Many participants discussed the impact of expected societal roles, the handicap level, and their perception of their role functioning with regard to occupational roles, family roles and other relationship roles. It also appeared that the buffers and exacerbating factors as represented within or external to the individuals, were considered with various items. Issues such as attendant care, environmental barriers, personal strengths and weaknesses were discussed in terms of how they affected their QOL.

When asked about difficulty understanding the questions, most participants felt the items were clearly worded. A few individuals commented on the need to re-read the question or think about the topic carefully before answering, but still felt that the questions were straightforward. Most participants did not feel uncomfortable about answering the questions although two individuals did mention specific topics that they felt slightly uncomfortable about but were still able to discuss with the investigator. It was particularly interesting to explore the familiarity issue with the participants. It became apparent from their comments that their comfort level was associated with the fact that the investigator/ interviewer was a health care professional who had worked with individuals with SCI and was married to someone with a spinal cord injury. Examples of some of the comments included: "you live with someone who's disabled and so you know" and "you have an understanding of my world". This background information about the investigator was available to all participants, as it was part of the introduction in the letter sent requesting participation in the study. None of the participants felt that answering the questionnaire was emotionally difficult, however one individual did comment that he thought that asking questions like this should be done at least one year after a spinal cord injury. Indeed, part of the eligibility criteria for this study was that participants be at least one year post injury and therefore likely to be more able to consider emotionally difficult issues without distress.

### Objective 2 – Structural Component

#### Domain Recognition

The participants were asked to group the QLI items as they felt the items "fit together", the objective being to examine the item interrelationships identified by the participants as compared to the original domains of the QLI. The number of groupings of items by the participants ranged from 4 to 11, with five participants having made grouping of eight items. The actual item groupings of each participant are in Appendix Q. Each grouping represented a different domain according to the participant. The number of items per group ranged from one to twelve. The proportional agreement of item pairings within and between domains is presented in Table 4-2. The low values along the diagonal of the table indicate that there is not very good agreement with the four domain structure conceptualized by the QLI developer (Appendix R). Comparison of the participant groupings with the QLI domains revealed that there were some consistent patterns with which certain items were categorized. The patterns of groupings will be presented descriptively within the context of the existing domains of the QLI with consideration of the theoretical framework of disablement.

Within the health and functioning domain, which has 16 items, the participants' groupings of items 1 through 9 were most evident. Ninety percent of the participants grouped items 1 through 4 together and 55% included item 9 with these four. The grouping of items 1 to 4 (health, health care, pain and clear lungs) are consistent with the level of impairment of the theoretical framework which involves the recognition by the individual of dysfunction in one or more body systems. For items 5 through 8, 64% of the participants grouped three of these four items together in the same category. These items reflect the concept of disability in which the individual is restricted from performing

**Table 4-2** Proportion of item pairings within and between domains

| | H & F | S & E | P & S | F |
|---|---|---|---|---|
| H & F | $\frac{551}{2640}$ = **.21** | $\frac{121}{1584}$ = **.08** | $\frac{158}{1232}$ = **.13** | $\frac{100}{704}$ = **.14** |
| S & E | | $\frac{180}{792}$ = **.23** | $\frac{87}{693}$ = **.13** | $\frac{69}{396}$ = **.17** |
| P & S | | | $\frac{158}{462}$ = **.34** | $\frac{37}{308}$ = **.12** |
| F | | | | $\frac{56}{132}$ = **.42** |

Abbreviations:
H & F – Health and Functioning; S & E – Social and Economic; P & S Psychological and Spiritual; F - Family

The numerator of the equation in each cell represents the number of item pairings by all participants and the denominator represents the total number of possible item pairings for all participants.

tasks that would be considered "normal" such as personal care and the ability to go places and also reflects the intraindividual factors of energy and control that may affect the level of disability. Item 14 (sex life) from the health and functioning domain, was grouped by 73% of the participants with item 13 (spouse, lover or partner) which is an item from the family domain. Similarly, item 15 (ability to have children) was grouped with at least two other items from the family domain by 45% of the participants. Item 19, concerning family responsibilities was categorized with other items from the health and functioning domain (45%) or other items from the family domain (36%). The item of family responsibilities reflected the relationship of two levels of the theoretical framework, disability and handicap. This was supported by the interview data in which the participants discussed their restriction of physical skill (disability) but with specific reference to how this affected their family role (handicap). Only 36% of the participants grouped items 20 (usefulness to others) and 28 (do things for fun) with other items primarily from the health and functioning domain, no other pattern was evident. There were no set patterns to the categorization of items 21 (worries) and 29 (happy future), however 27% of the participants grouped these items with other items from either the social and economic domain or the psychological and spiritual domain.

There seemed to be more consistency within the categorization of items from the social and economic domain. For items 16 through 18, the majority (90%) grouped at least two of the three items together, with 36% including all three in the same category. These items, which concern friends and family are indicated at the handicap level, specifically the participation in social relationships. Similarly, there was 90% agreement that items 22 and 23, neighborhood and home, should be grouped together and 5 participants grouped these two items as a separate category. These two items represent an extraindividual factor, the physical environment which can affect any level of the disablement process. Items concerning job, education and finances (24 through 27) were grouped together by 55% of the participants. These items would encompass risk factors (pre-existing level of education, employment) as well as extraindividual factors which could facilitate or inhibit the opportunity for the person to obtain further education, find or maintain a job and subsequently have adequate financial support.

Items 30 through 36 constitute the psychological and spiritual domain of the QLI. At least four of the seven items were grouped together by 64% of the participants. Of those that grouped at least four items together, 36% categorized items 33 through 36 together. Four individuals recognized item 31 (faith in God) as a separate category. All of these items indicate intraindividual factors, which can affect any level of the main pathway. The distinct recognition of item 31 may indicate that spirituality is separate from other psychosocial attributes that are part of the intraindividual factors.

The family domain of the QLI contains the fewest items (10 through 13), and with the exception of one item (item 13), there was fairly consistent agreement regarding categorization. Items concerning family health, family happiness and children (10-12) were grouped together by 45% of the participants. These items may best represent the handicap level, specifically social integration within the family. Item 13 (spouse, lover or partner) was most commonly grouped together with items 14 and 15 (sex life and the ability to have children) from the health and functioning domain, with 45% of the participants in agreement with this categorization. The grouping of these items appear to be consistent with the level of disability, in which the participant may be considering activities of everyday life that they can no longer perform in the "normal" manner.

### Scoring Model

To determine if both satisfaction and importance had a role in the consideration of QOL as implied by the scoring procedures, comparisons were made of the participants' item rankings and their corresponding weighted scores as well as the weighted QLI total score with the non-weighted satisfaction section and importance section scores. Descriptive results of the participants' scores for the overall QLI and each domain are presented in Table 4-3. For the results of the item ranking exercise, descriptive analyses of the correlations for the participant's ranking of the items and the corresponding weighted scores for each domain are presented in the stem and leaf plots (figure 4-1). The highest average correlation was obtained for the family domain (0.59), with the correlations ranging from –1.0 to 1.0 for the eleven participants. The average correlations for the remaining three domains were similar: health and functioning (0.28); psychological and spiritual (0.26); and social and economic (0.38). The range of correlations from negative to positive was evident for all domains.

**Table 4-3** Descriptive results of the QLI scores* (N = 11)

| Domains | Mean | Standard Deviation | Minimum | Maximum |
|---|---|---|---|---|
| Health & Functioning | 18.2 | 3.03 | 12.38 | 21.84 |
| Social & Economic | 20.56 | 2.99 | 14.5 | 24.75 |
| Psychological & Spiritual | 20.19 | 4.99 | 10.29 | 27.14 |
| Family | 23.09 | 3.36 | 17.5 | 27 |
| Overall | 19.59 | 3.0 | 13.12 | 23.15 |

* Possible scores range from 0 to 30

| **H & F** | **S & E** | **P& S** | **F** |
|---|---|---|---|
|  |  | -0 . 6 |  |
| -0 . 11 | -0 . 34 | -0 . 2 | -1 . 0 |
| 0 . 001133 | 0 . 0044 | 0 . 1124 | 0 . 244 |
| 0 . 567 | 0 . 55789 | 0 . 55569 | 0 . 899 |
|  |  |  | 1 . 000 |

**Figure 4-1** Stem and Leaf Plots: Correlations examining the agreement of the participants ranking of the items in each domain with the corresponding weighted scores.
Stem width: 1; Each leaf: 1 case
Note: family domain, N = 10 since weighted scores were constant

Given these results, additional analyses of the relationships between the participant's ranking of the items and the corresponding satisfaction and importance scores were carried out and are presented in the stem and leaf plots of figure 4-2 and 4-3. These analyses were meant to determine if the decision process for the ranking of the items favored either the consideration of satisfaction or importance as opposed to the combination of the two as conceptualized in the scoring model. The range of correlations from negative to positive for the relationship of the item ranking with the satisfaction scores are similar to the results for the weighted scores. Although there were some instances in which the importance scores were constant (predominantly in the family domain), the correlations are all positive and most are above 0.4, indicating that perhaps the importance of the life aspect was the primary criterion for the ranking decisions. Comparison of the correlations of the items per domain with each of the three possible corresponding scores for each participant are presented in Table 4-4. These results indicate that the decision for item ranking was most often based on a combination of importance and satisfaction (similar correlations for all three rank:score possibilities) or primarily importance (highest of the three correlations). The ranking of the items within each domain by the participants and the corresponding satisfaction, importance and weighted scores are presented in Appendix S.

| **H & F** | **S & E** | **P & S** | **F** |
|---|---|---|---|
|  | - 0 . 5 | - 0 . 5 |  |
| - 0 . 122 | - 0 . 13 | - 0 . 3 | -1 . 0 |
| 0 . 001444 | 0 . 0034 | 0 . 1234444 | 0 . 044 |
| 0 . 66 | 0 . 6689 | 0 . 59 | 0 . 899 |
|  |  |  | 1 . 000 |

**Figure 4-2** Stem and Leaf Plots: Correlations examining the agreement of the participants ranking of the items in each domain with the corresponding satisfaction score.
Stem width : 1; Each leaf: 1 case
Note: family domain, N = 10 since satisfaction scores were constant

| **H & F** | **S & E** | **P & S** | **F** |
|---|---|---|---|
| 0 . 022334444 | 0 . 034 | 0 . 0134 |  |
| 0 . 67 | 0 . 56667888 | 0 . 67888 | 0 . 888 |

**Figure 4-3** Stem and Leaf Plots: Correlations examining the agreement of the participants ranking of the items in each domain with the corresponding importance score.
Stem width : 1; Each leaf: 1 case
Note: family domain, N = 3 and psychological and social domain, N = 9 since importance scores were constant

**Table 4-4** Correlations of participant's ranking of the items within each domain and the corresponding weighted total scores, satisfaction scores and importance scores

| | **Health & Functioning** | **Social & Economic** | **Psychological & Spiritual** | **Family** |
|---|---|---|---|---|
| **Subject** | **Correlations W, S, I*** | **Correlations** | **Correlations** | **Correlations** |
| 1 | -.1, -.14, .49 | .05, .05, .0 | -.56, -.56 | .96, .96 |
| 2 | .12, .09, .46 | .83, .82, .85 | .18, .18 | 1.0, 1.0 |
| 3 | .04, -.28, .60 | .77, .66, .37 | .53, .49, .81 | -1.0, -1.0 |
| 4 | .37, .46, .46 | .43, .39, .63 | .37, .46, .46 | .40, .40 |
| 5 | .07, .06, .48 | .05, -.10, .66 | .94, .94, .88 | |
| 6 | -.17, -.17, .36 | -.35, -.31, .85 | .11, .46, .62 | 1.0, 1.0 |
| 7 | .17, .16, .02 | -.41, -.57, .50 | .45, .40, .31 | .24, .0, .86 |
| 8 | .74, .64, .73 | .52, .44, .41 | .57, .31, .86 | .86, .86, .86 |
| 9 | .51, .41, .28 | .43, .09, .86 | .55, .47, .40 | 1.0, 1.0 |
| 10 | .69, .68, .24 | .58, .63, .76 | -.28, -.31, .14 | .44, .44 |
| 11 | .37, .36, .44 | .94, .91, .60 | .28, .29, .0 | .99, .95, .86 |

* Correlations of item ranking with corresponding Weighted Scores, Satisfaction Scores, Importance Scores.

Note: Absence of a correlation value indicates that the correlation could not be calculated since one variable was constant.

Correlations were calculated between the average weighted total QLI score and the average scores for the satisfaction and importance sections independently. The weighted total QLI score is highly correlated with the average satisfaction score (0.98) and not correlated with the average importance score (-0.05), as represented in scatter plots of figures 4-4 and 4-5. Similar results were obtained when each domain was analyzed separately. The average satisfaction score for each domain was highly correlated with the domain QLI score, with correlations ranging from 0.95 to 0.99. The range of correlations between the QLI scores and the average importance scores for each domain were –0.19 to 0.33. These results indicate that the importance section may not be providing the weighting as conceptualized in the scoring model.

However, when the outlier data point is removed (figure 4-6), the correlation between the weighted total QLI score and the importance section score improves to 0.47 indicating some contribution from the importance scores. Given that an odd data point can significantly influence the results with a small sample, the relationship between the weighted total QLI score and the satisfaction and importance section scores for the larger sample from Phase 2 (n = 98) were analyzed. The weighted total QLI was highly correlated with the average satisfaction score (r = 0.99) and moderately correlated with the average importance score (0.43). These results are almost identical to the Phase 1 results when the outlier was removed, providing further evidence that the importance scores are making some contribution to the overall score.

Considering the lower correlation between the importance score and weighted total QLI score, the variance of scores for the satisfaction and importance sections were also examined. The respondents used the range of score responses for each section, however the distribution was different. For the satisfaction section, the percentage of selection of scores from 3 to 6 ranged from 10% to 37%, accounting for a total of 89%. The most frequently selected option was a score of five. For the importance section, selection of a score of five or six accounted for 82% of the total. It is interesting to note that 8 out of 11 participants showed no variance in the importance scores for the 4 items from the family domain and that 2 out of 11 participants showed a similar trend for the 7 items from the psychological and spiritual domain. This may indicate that the bipolar scale anchors are not sufficient, especially for domains with few items.

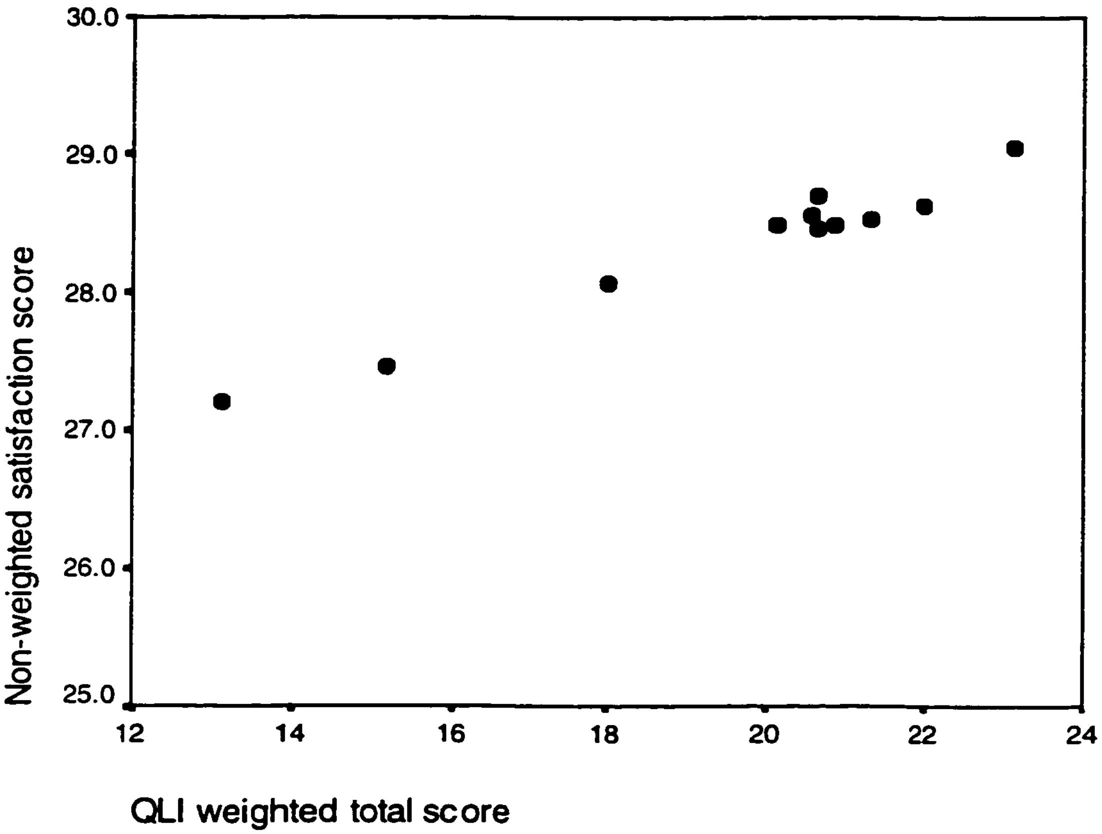

**Figure 4-4** Relationship between weighted total QLI scores and the non-weighted satisfaction scores (r = 0.98)

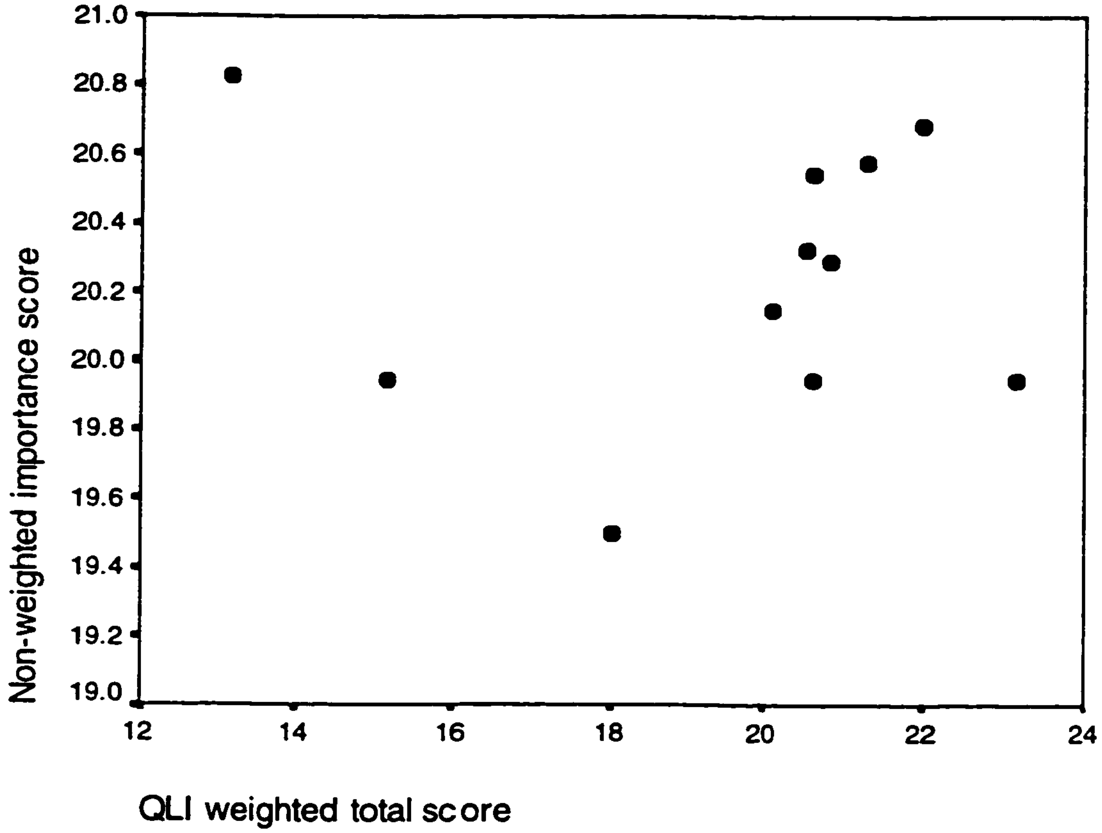

**Figure 4-5** Relationship between weighted total QLI scores and the non-weighted importance scores (r = - 0.05)

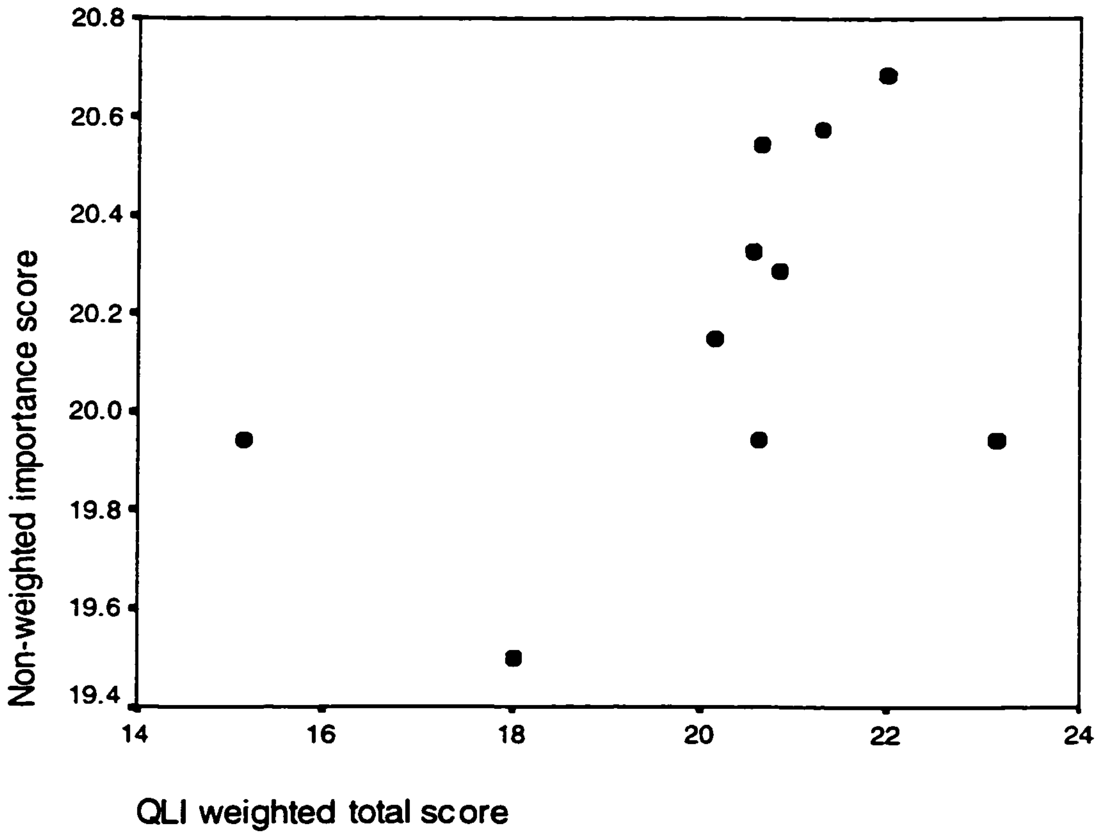

**Figure 4-6** Relationship between weighted total QLI scores and the non-weighted importance scores - outlier removed (r = 0.47)

**Phase 2**

Sample recruitment involved mailing a total of 373 letters to potential participants inviting participation in the study. Twenty-five letters were returned to the sender and 129 responses were received by the investigator, a response rate of 37.1 %. Of those responses received, 112 were willing to participate, and 17 were not willing or unable to participate. Eight individuals that responded did not meet the inclusion criteria and those not interested in participating mostly stated they were too busy. Fourteen of the individuals willing to participate lived a distance that was too far for the investigator to travel therefore, 98 individuals participated in this phase of the study. There were 76 males and 22 females ranging in age from 21 to 81 years with the average age being 45.2 years (s.d. 14.9). The average time since injury was 15.5 years with a range of 1.1 to 77.7 years. Ten individuals were attending school either full time or part time. Detailed information regarding level of injury, living accommodation, marital status, employment status, and education status is presented in Table 4-5.

Many characteristics of this sample are similar to the characteristics of other studies of quality of life for individuals with SCI (Clayton & Chubon, 1994; Fuhrer et al., 1992; Lundqvist et al., 1991; Post et al., 1998). Like this sample, other studies have been predominantly male (ranging from 71 to 88%), have almost an even split of persons with quadriplegia and persons with paraplegia, and have a lower employment rates (29 to 31.4%) in comparison to the general population. The percentage of married persons varied widely across studies (29 to 63%), however the marital status for this sample does fall within this range. Two studies (Fuhrer et al., 1992; Lundqvist et al., 1991) reported similar high levels of education with 53 and 67 percent of individuals respectively having at least some post secondary schooling. The sample in this study is different on two characteristics. On average this sample was older, an average age of 45.2 years compared to the average ages reported in the literature (means of 33.5 to 39.5 years). Also the duration of injury, on average was longer at 15.5 years as compared to means of 2.3 to 10.6 years. This may be due to the fact that 11 participants over the age of 45 had been injured more than thirty years. Without these participants, the sample is still older (mean = 43.1) and the average duration of injury is still longer at 11.9 years.

**Table 4-5** Descriptive information for the 98 participants
(N males = 76, N females = 22)

| Characteristic | Number | Percent |
|---|---|---|
| **Level of Injury** | | |
| Cervical | 55 | 56.1 |
| Thoracic | 35 | 35.7 |
| Lumbar | 8 | 8.2 |
| | | |
| Complete | 55 | 56.1 |
| Incomplete | 43 | 43.9 |
| | | |
| **Employment Status** | | |
| Full time | 29 | 29.6 |
| Part time | 9 | 9.2 |
| Unemployed | 43 | 43.9 |
| Retired | 17 | 17.3 |
| | | |
| **Education Status** | | |
| Elementary School | 3 | 3.1 |
| Jr. High School | 9 | 9.2 |
| High School | 28 | 28.6 |
| Trades Certificate | 12 | 12.2 |
| Some Post Secondary | 14 | 14.3 |
| College Diploma | 18 | 18.4 |
| Bachelors Degree | 12 | 12.2 |
| Masters Degree | 2 | 2.0 |
| | | |
| **Marital Status** | | |
| Married or Common Law | 48 | 49 |
| Separated | 4 | 4.1 |
| Divorced | 8 | 8.2 |
| Single | 38 | 38.8 |
| | | |
| **Living Arrangements** | | |
| Own House or Condo | 57 | 58.2 |
| Rent House | 14 | 14.3 |
| Rent Apartment | 23 | 23.5 |
| Long Term Care Facility | 4 | 4.1 |

## Objective 1 – External Component

Although not a specific objective, the effect of the potential intervening variables was analyzed. The examination indicated that age was not significantly correlated with quality of life ($r = -0.04$), while the time since injury was significantly correlated ($p < 0.05$) although the magnitude of the correlation was small ($r = .21$). These results suggest that age does not affect QOL but the duration of the injury may have some impact on QOL. Based on the analyses of variance (Appendix T), the mean QLI scores were not significantly different among the categories for gender, level of injury, employment status, educational status, marital status, or living arrangements.

The examination of the external component involved an analysis of the relationships between QOL and the other concepts identified in the theoretical model. The descriptive results for the scores on the measurements of the dependent and independent variables are presented in Table 4-6. In addition, Table 4-7 lists the items of the QLI with the highest and lowest weighted scores. The scores on the QLI were compared to five other measures to examine the a priori hypotheses of relationships. Three of the five hypotheses regarding the associations were supported. The QLI was not significantly related to the level of impairment as measured by the ASIA motor score, the correlation being 0.06. As expected the QLI was significantly related to the measure of handicap, the Reintegration to Normal Living Index and the magnitude of the correlation was as predicted at –0.65. The QLI was also significantly related to self esteem ($r = 0.61$), an intraindividual factor that can mediate the disablement process, and again the magnitude of the correlation was as predicted.

Two hypotheses were not supported by the data. The QLI was found to be significantly ($p < 0.05$) associated with the level of disability as measured by the Functional Independence Measure, however the magnitude of the correlation was quite low at 0.20. There was no relationship between the QLI and locus of control as measured by Rotter's Internal-External Locus of Control Scale. It was hypothesized that there would be a significant moderate correlation (0.4) with this construct as locus of control is indicated in the theoretical framework as an intraindividual factor that could mediate the disablement process. The relationships among all of the measurements are presented in Table 4-8.

**Table 4-6** Descriptive results for participants' scores on the six measurements (N = 98)

| Instrument | Mean | Standard Deviation | Range* |
|---|---|---|---|
| **QLI** | | | |
| Overall | 21.01 | 4.27 | 11 - 30 |
| Health & Functioning | 19.92 | 4.83 | 6.38 - 30 |
| Social & Economic | 21.56 | 4.26 | 11.75 - 30 |
| Psychological & Spiritual | 21.74 | 5.49 | 5.64 - 30 |
| Family | 22.94 | 5.58 | 8 - 30 |
| **ASIA** | 43.38 | 26.09 | 0 - 98 |
| **FIM** | 62.58 | 25.57 | 18 - 91 |
| **RNL** | 23.05 | 13.54 | 3 - 78.36 |
| **RSES** | 31.29 | 5.42 | 19 - 40 |
| **LOC** | 9.1 | 3.75 | 0 - 17 |

* Ranges of possible scores for the QLI: 0 to 30; ASIA: 0 – 100; FIM: 13 to 91; RNL: 0 to 100; RSES: 10 to 40; LOC: 0 to 23

Abbreviations: QLI – Quality of Life Index; ASIA – American Spinal Injury Association (motor score); FIM – Functional Independence Measure; RNL – Reintegration to Normal Living (Index); RSES – Rosenberg Self Esteem Scale; LOC – Locus of Control.

**Table 4-7** Ranking of weighted QLI items for all participants unless otherwise noted

| Highest weighted items | Score* | Lowest weighted items** | Score |
|---|---|---|---|
| Children (n=56) | 11.96 | Not having a job (n=61) | - 2.20 |
| Emotional support from family | 9.42 | Not having a spouse, lover or partner (n=36) | - 1.25 |
| Family's health | 8.64 | Amount of pain you have | - 0.74 |
| Home, place where you live | 8.45 | Sex life | 0.01 |
| Friends | 8.38 | Ability to have children (n=86) | 1.74 |
| | | Amount of worries in your life | 2.57 |

* Scores range from a minimum of –15 to a maximum of +15.

** Scores for the remaining items ranged from 4.46 to 7.98

**Table 4-8** Correlation matrix of all measured variables for Phase 2 (N = 98)

| **Variable** | QLI | ASIA | FIM | RNL | RSES | LOC |
|---|---|---|---|---|---|---|
| QLI | 1.000 | 0.058 | 0.202* | -0.654** | 0.609** | -0.024 |
| ASIA | | 1.000 | 0.847** | -0.196 | 0.054 | -0.12 |
| FIM | | | 1.000 | -0.348** | 0.171 | -0.175 |
| RNL | | | | 1.000 | -0.483** | -0.042 |
| RSES | | | | | 1.000 | -0.242* |
| LOC | | | | | | 1.000 |

** Correlation is significant at the 0.01 level (2-tailed).
* Correlation is significant at the 0.05 level (2-tailed).

Abbreviations: QLI – Quality of Life Index; ASIA – American Spinal Injury Association (motor score); FIM – Functional Independence Measure; RNL – Reintegration to Normal Living (Index); RSES – Rosenberg Self Esteem Scale; LOC – Locus of Control.

**Objective 2 – Structural Component**

The objective for this part of Phase 2 was to further evaluate the domains of the QLI through exploratory factor analysis. Complete data for factor analysis were available for 80 out of 98 participants. Four items are complementary (have/ do not have a spouse; have/ do not have a job) and another item only applied to those that have children so there was a large number of missing data points for these five items therefore, they were not included in the factor analysis. It was determined that it did not make sense conceptually to apply the mean score to the missing data points in order to include them in the analysis. Therefore, 32 items were subjected to the factor analysis. Given the small sample size and the deletion of five items from the analysis, these results should be interpreted with caution. The analysis does however give some indication of potential structure differences for the domains of QOL for individuals with SCI and the domains as conceptualized by the developer, which were analyzed with a group of patients undergoing hemodialysis. Structure differences would indicate the use of subscores based on separate domains are not applicable when applying the measure to another patient population than that for which it was originally validated.

The principal components analysis provided the first two criteria to identify the simple factor solution. Using Kaiser's criterion, there were 7 components with eigenvalues greater than 1. Plotting the eigenvalues of all of the items to obtain the scree plot indicated a 6 factor solution. The image factor analysis also produced a six factor solution for simple structure. Using the principal axis extraction method with a varimax rotation, the 7 factor matrix showed too much factorial complexity with 16 items loading on two or three factors using a minimum loading value of 0.3. This would be expected as an orthogonal solution implies that the factors are uncorrelated and this situation would be unlikely in a measure of QOL.

Five, six and seven factor pattern matrices were derived using the principal axis extraction method with an oblimin rotation. The seven factor solution was the least desirable when analyzed according to the criteria. Firstly, there were 2 factors that only contained two items, which really should not constitute a factor (Norman & Streiner, 1994). Two items did not load on any factors using the 0.4 criterion level and 5 items showed factorial complexity, including one item that loaded on three factors. The six factor solution was not much better. There were three items that did not load on any factor and 4 items that showed factorial complexity. One factor had only three items and although it could be considered a factor, the nature of the items did not seem to fit together conceptually. If the criterion for the factor loading was decreased to 0.3, there was one item that still did not load on a factor and one factor showed bipolarity, with both positive and negative loadings. In addition, 13 items now showed factorial complexity, with two items loading on three factors.

Although there still were problems, the five factor pattern matrix appeared to indicate the best factor solution since the variances were more equally distributed across the factors and each factor was comprised of 5 to 7 items. The total five factor structure accounted for 54.7 percent of the variance. The loadings of the items on the pattern matrix for the five factors are shown in Table 4-9. Using the 0.4 loading criterion, there were 4 items that did not load onto any factor and 2 items that showed factorial complexity. When the criterion was 0.3, all items loaded onto a factor, however the factorial complexity increased with 6 additional items loading on 2 factors. In the cases of factorial complexity, when one loading was substantially higher on one factor as compared to the other four factors, the highest loading was considered salient (Gorsuch, 1983). The fit of the loadings on each factor was further corroborated by conceptual fit.

Six items loaded saliently on the first factor. Five of the six items appear to be directly related to happiness or self-fulfillment, an intrinsic quality for the individual. The item pertaining to sex life did appear to fit conceptually within this grouping especially when reviewing the interviews of the 11 participants in Phase 1. Many of these individuals discussed the issue of "intimacy" and "the emotional side" that goes beyond the physical act of sex as being very important when they think of a sexual relationship. Research has shown that the loss of sexual functioning is least important among other functional losses and that psychosocial factors are more important for a satisfying sexual life and relationship (Hanson & Franklin, 1976; Kreuter et al., 1996).

The second factor contained 8 items that seemed to reflect a theme of family or community relationships. The items of the QLI that loaded onto this factor were very similar to the issues described in the category of "relationships" in two separate qualitative studies of quality of life (Bach & McDaniel, 1993; Pain et al., 1998).

Although the item concerning neighborhood did not have a high loading on this factor it certainly would fit conceptually if considering the social aspects of a neighborhood. The item of health care does appear to be out of place, however one of the issues of health care discussed by the participants in Phase 1 focused on the relationship between themselves and their attendant or residential aide.

Six items loaded saliently on the third factor. All of the items appeared to be concerned with the issue of functional independence. The item pertaining to control also loaded highly on the first factor but was retained in this factor based on the higher loading. The issue of control may have a psychological component to it as discussed in a qualitative study involving participants with SCI (Bach & McDaniel, 1993). However, the participants in Phase 1 of this study focused primarily on physical functioning when discussing the item pertaining to control over their life. Two other items also showed factorial complexity. The item concerning the ability to go places also loaded on the fourth factor. There seemed to be two distinct issues discussed by the participants in Phase 1, one concerning the independence associated with being able to drive a vehicle, and the other concerning the restrictions due to the accessibility of the location. Further conceptual clarity may be added by dividing this item into two, one relating to transportation and the other relating to accessibility. The item pertaining to family responsibilities also loaded on the fourth factor. It was retained in this grouping based on the higher loading and discussions from participants in Phase 1. They focused heavily on their functional capabilities with respect to their families, which included issues of parenting, housekeeping, and helping out both physically and intellectually.

The fourth factor contained 5 items mostly representing an issue surrounding the intrinsic and extrinsic life circumstances that can impact an individual's situation either positively or negatively. The extrinsic aspects include an individual's financial situation as well as educational status. These can affect or be affected by the intrinsic aspect of the person's ability to deal with the worries in their life. Also, the intrinsic ability to cope with pain has been shown to be a great impediment to overall adjustment to spinal cord injury with subsequent low ratings for QOL (Stensman, 1994). The item pertaining to the things you do for fun seemed to be an odd fit with this group, however comments from participants in Phase 1 clarified the possible connection. For example, some individuals spoke of the lack of finances in limiting their ability to do things for fun. In addition when discussing the item about worries, some participants made a connection between aspects of life that would normally be considered fun, such as playing with their children, but now caused them to worry because of their inability to help in the event of an accident. Levi et al. (1996) has described the psycho-social and financial consequences of spinal cord injury, which includes restricted leisure activities and concerns about their financial situation.

Most of the 7 items that loaded on to the fifth factor seemed to reflect the issue of health and wellness especially the items related to health, energy and the chance of living a long time. The item regarding personal appearance made sense conceptually since many individuals from Phase 1 referred to their lack of muscle tone, strength and ability to maintain correct posture despite efforts to exercise and diet. The item reflecting goals and achievements does fit within this grouping. The opportunity to work is one of the primary goals or achievements that contributes to the quality of life for persons with spinal cord injury (Boswell et al., 1998). The advent of secondary psychological or physical health complications such as depression, bladder infection or skin breakdown can greatly affect the ability of a person with SCI to secure and maintain gainful employment (Athanasou, 1996; Krause, 1998b). The role of spirituality and faith in the lives of persons with disabilities is being recognized, however there is little research that elucidates its role during and after rehabilitation (Underwood-Gordon et al., 1997). Strong spiritual beliefs have been shown to be related to psychological and physical health in people with disability and chronic illness as well as those with acute medical illness (de Rozario, 1997; Koenig, 1998). The item regarding the ability to have children was added to the QLI to address the health issue surrounding the physical capabilities of an individual with SCI and so would conceptually fit within this factor although the loading is not very strong.

**Table 4-9** Loadings of items on factors from the pattern matrix for the five factor model

| | | | Factor Loadings* | | |
|---|---|---|---|---|---|
| **Item** | **I** | **II** | **III** | **IV** | **V** |
| Chances for a happy future | .781 | | | | |
| Happiness in general | .736 | | | | |
| Life in general | .659 | | | | |
| Peace of mind | .586 | | | | .310 |
| Yourself in general | .433 | | | | .390 |
| Your sex life | .326 | | | | |
| Emotional support from family | | .769 | | | |
| Health care | | .696 | | | |
| Family's happiness | .326 | .686 | | | |
| Home, Place where you live | | .675 | | | |
| Family's health | | .654 | | | |
| Your friends | .304 | .496 | | | |
| Emotional support from others | | .459 | | | .344 |
| Neighborhood | | .309 | | | |
| Ability to take care of yourself | | | .751 | | |
| Ability to go places | | | .634 | .361 | |
| Usefulness to others | | | .618 | | |
| Ability to clear your lungs | | | .535 | | |
| Control of your life | .432 | | .529 | | |
| Take care of family responsibilities | | | .455 | .423 | |
| Take care of financial needs | | | | .717 | |
| Amount of worries in your life | | | | .586 | |
| Your education | | | | .538 | |
| Things you do for fun | | | | .487 | |
| Amount of pain you have | | | | .423 | |
| Your personal appearance | | | | | .642 |
| Health | | | | | .529 |
| Chances of living a long life | | | | | .480 |
| Achievement of personal goals | | | | | .445 |
| Energy for everyday activity | | | | | .406 |
| Your faith | | | | | .391 |
| Ability to have children | | | | | .312 |

* The salient loading for the items that loaded on two factors is underlined.

## Phase 3

The objective of this phase was to evaluate the predictors of QOL from data collected prospectively at one year post injury. Of the 98 participants from phase 2, only 28 individuals had also been part of the prospectively gathered data, which formed the database (Reid et al., 1992). Through the office of the Canadian Paraplegic Association, 33 additional letters were sent to persons that had incurred a traumatic spinal cord injury between the years 1983 and 1991. Included with the letters explaining the study, was a consent form and the demographic information data sheet along with a copy of the QLI as revised for Phase 2. Fourteen individuals sent back the consent form and questionnaires in the stamped return envelope, a response rate of 42.4%. Thus the total sample size for this phase of the study was 42. However, only 37 of the 42 participants who had complete data for the predictor variables in the database were included in the regression analysis.

The 29 males and 8 females ranged in age from 22 to 78 years (mean = 34.7) with an average duration of injury of 9.4 years (range = 5.7-14.5). Twenty-four persons had sustained a cervical level injury while the other 13 had either a thoracic or lumbar injury. There was a more even split for employment status with 45.9 % working and 51.4 % unemployed and one individual retired. The majority of participants had at least some post secondary education (62.2 %) and 9 of the participants were currently attending school. There was an even number of married and single participants (n = 16 in each category) with 5 persons that were either separated or divorced. Twenty-one participants owned their home, 15 were renting and one lived in an long-term care facility. Except for the slightly higher percentage of employed individuals, the characteristics of this sample are very similar to previous studies of QOL involving persons with spinal cord injury (Clayton & Chubon, 1994; Fuhrer et al., 1992; Lundqvist et al., 1991; Post et al., 1998).

For this sample, neither age nor time since injury was significantly associated with the mean QLI scores, with correlations of r = -0.15 and r = 0.262 respectively. The magnitude of the correlation of the QLI with time since injury for this sample was greater than the correlation for the sample of 98 participants, thus the non-significant result may reflect sample size. Similar to the sample of 98 participants, there were no significant differences for the mean QLI scores for the categories of gender, level of injury, employment status, educational status, marital status or living arrangements. The results for the ANOVA analyses can be found in Appendix U.

Descriptive results for the scores of the 37 participants on the QLI and each of the predictor variables are presented in Tables 4-10 and 4-11. The distribution of the interval level variables, the QLI, the FIM and the ASIA motor scores are represented in figures 4-7, 4-8 and 4-9. Univariate analyses indicated that there were no significant associations between the total QLI score and any of the predictor variables. The ASIA motor score was found to be significantly associated with all of the other predictor variables. The FIM score was also significantly correlated with the categorical variables for walking status and pain status. The associations between all of the variables is presented in Table 4-12.

The results of the forced regression analysis presented in Table 4-13 indicate that none of the variables of impairment, disability or handicap that were included in the database were sufficient predictors of QOL. The variance accounted for is less than 20% as evident in the ANOVA analysis of the ability to predict QOL from the 5 variables (Table 4-14). The coefficients of regression for the 5 predictor variables included in Table 4-15 indicates that both pain and walking approached significance. Since the ASIA motor score was significantly correlated with all of the predictor variables, an additional regression analysis was performed with the ASIA removed to determine if the results would change. The results were similar in that none of the variables were significant predictors of QOL, however the walking variable which was highly correlated with the ASIA score no longer approached significance.

**Table 4-10** Descriptive results for the QLI, ASIA motor score and the FIM (N = 37)

| Variable | Mean | Standard Deviation | Range |
|---|---|---|---|
| QLI | 20.38 | 3.75 | 11.74 – 26.69 |
| ASIA | 41.0 | 25.8 | 0 - 100 |
| FIM | 63.97 | 24.91 | 17 - 91 |

**Table 4-11** Descriptive results for the variables of Pain, Walking and Employment

| Variable | Number | Percent |
|---|---|---|
| **Pain** | | |
| Yes | 17 | 45.95 |
| No | 20 | 54.05 |
| **Walking** | | |
| None/ Exercise Only | 29 | 78.38 |
| Functional with/without aids | 8 | 21.62 |
| **Employment** | | |
| Yes | 8 | 21.62 |
| No | 29 | 78.38 |

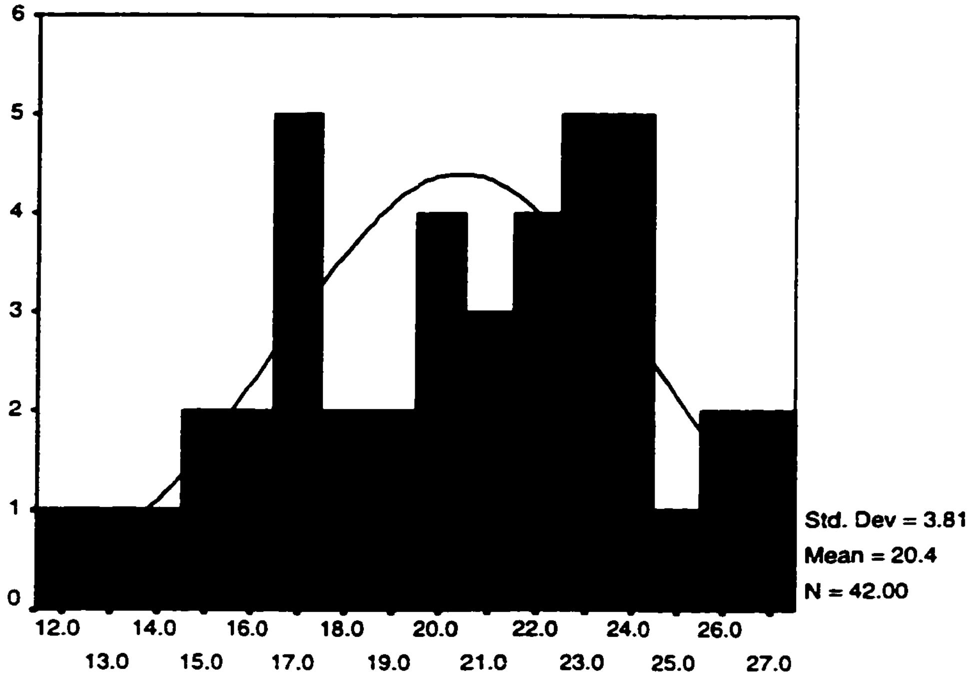

Figure 4-7 Distribution of the scores for the Quality of Life Index

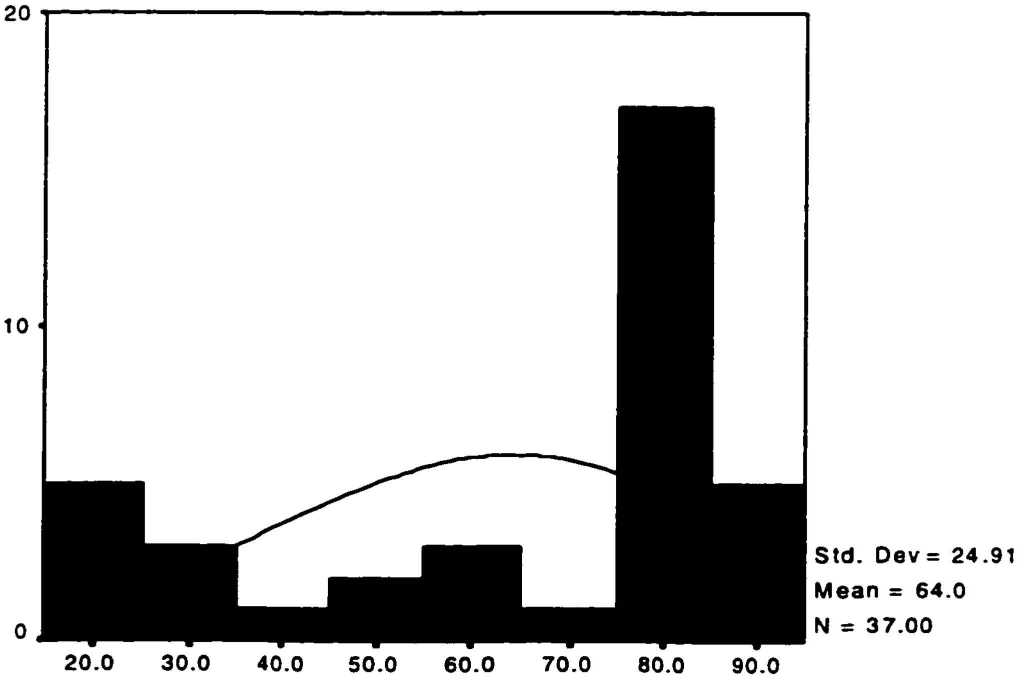

Figure 4-8 Distribution of the scores for the Functional Independence Measure

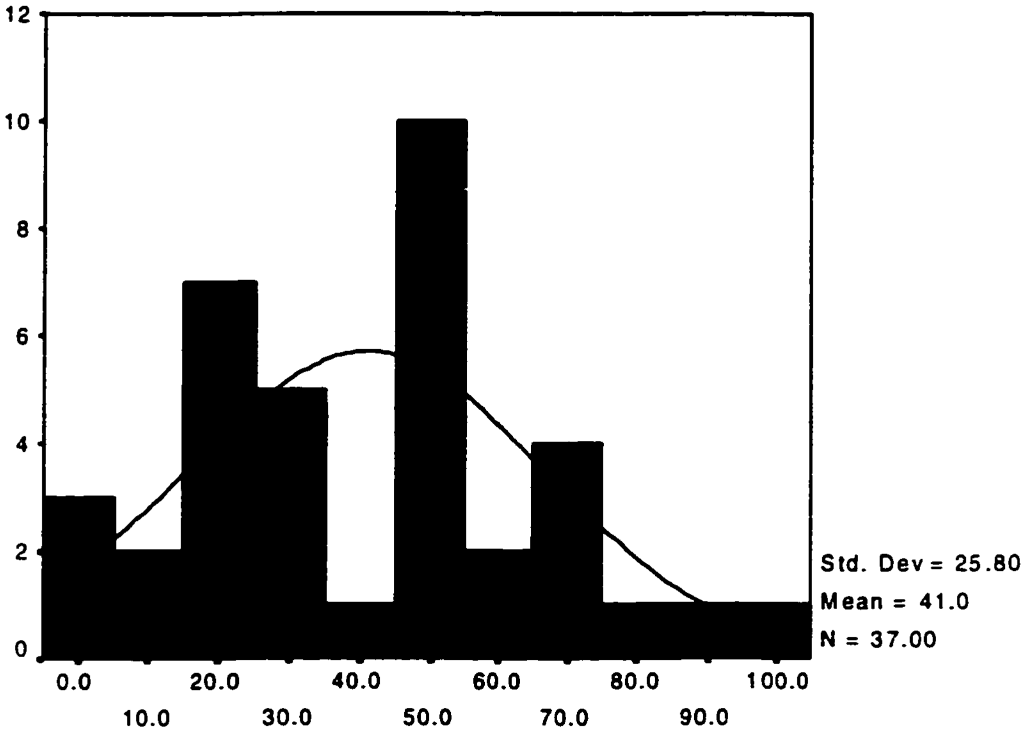

**Figure 4-9** Distribution of the ASIA motor scores

**Table 4-12** Correlation matrix among the QLI and potential predictor variables (N = 37)

| Variable | QLI | ASIA | Pain | Walking | FIM | Employed |
|---|---|---|---|---|---|---|
| QLI | 1.000 | .001 | -.247 | .166 | .050 | -.021 |
| ASIA | | 1.000 | .452** | .730** | .761** | -.369* |
| Pain | | | 1.000 | .306 | .416* | .089 |
| Walking | | | | 1.000 | .385* | -.203 |
| FIM | | | | | 1.000 | -.300 |
| Employed | | | | | | 1.000 |

** Correlation is significant at the 0.01 level (2-tailed).
* Correlation is significant at the 0.05 level (2-tailed).

**Table 4-13** ASIA motor score, pain, walking, FIM, and employment status regressed on the total QLI score

| R | $R^2$ | Adjusted $R^2$ | Std. Error of the Estimate |
|---|---|---|---|
| .423 | .179 | .047 | 3.659 |

**Table 4-14** ANOVA analysis of the ability to predict QOL from the 5 variables representing impairment, disability and handicap

| Model | Sum of Squares | Degrees of Freedom | Mean Square | F | P value |
|---|---|---|---|---|---|
| Regression | 90.57 | 5 | 18.12 | 1.353 | .27 |
| Residual | 415.12 | 31 | 13.39 | | |
| Total | 505.69 | 36 | | | |

**Table 4-15** Coefficients of regression for the 5 predictor variables

| | Unstandardized Coefficients | | Standardized Coefficients | | | 95% Confidence Interval for B | |
|---|---|---|---|---|---|---|---|
| Model | B | Std. Error | Beta | t | P value | Lower Bound | Upper Bound |
| (Constant) | 17.36 | 4.14 | | 4.1 | .00 | 8.91 | 25.81 |
| ASIA | -.06 | .056 | -.44 | -1.13 | .27 | -.18 | .05 |
| Pain | -2.57 | 1.44 | -.347 | -1.79 | .08 | -5.51 | .357 |
| Walking | 4.15 | 2.33 | .46 | 1.78 | .08 | -.60 | 8.89 |
| FIM | .05 | .04 | .37 | 1.34 | .19 | -.03 | .14 |
| Employment | .46 | 1.67 | .05 | .28 | .78 | -2.93 | 3.86 |

# V. Discussion

## Introduction

The current study was designed to address the validity of the Quality of Life Index with respect to the conceptualization of the components of validity introduced by Loevinger (1957). This chapter is organized such that the substantive, structural and external components of validity will be discussed with respect to the phases of the study in which they were addressed. The final phase of the study concerning the prediction of QOL will be discussed separately. Generally, the results of this study support both the substantive and external validity of the QLI within the theoretical framework that was applied. There are some concerns about the structural validity of the QLI with respect to the domains and the scoring model which indicate areas of future study. The results of the prediction of QOL were not completely as expected, however they do suggest additional areas to focus on with regard to outcomes in rehabilitation. Finally, the issues concerning generalizability and limitations of the results will be discussed followed by the implications for rehabilitation and future study.

## Substantive Component

This study has examined the cognitive tasks involved when individuals with spinal cord injury answer the items of the QLI in order to evaluate the substantive component of validity. Although the target population may be consulted about the item content in development stage of QOL instruments (Chubon, 1987; Ferrans & Powers, 1985; Spitzer et al., 1981), few studies have evaluated the response processes to the items in an empirical manner. Traditionally, evaluations of instrument content include the judgements of experts (Kerlinger, 1987; Lynn, 1986; Thorn & Deitz, 1989), although some individuals from a specific patient population may be included. An evaluation of the item content post-hoc is particularly important if the instrument was designed with a specific population and subsequently is to be used with other groups of individuals. With a measure that is tapping into a subjective, multidimensional construct, it seems logical that the experts evaluating the content would be the individuals whom researchers will be making inferences about. It is important to know that the responses generated by the individuals reflect processes that would indicate that the items are perceived as meaningful. If the items in a QOL measure do not include topics that best exemplify the construct, as perceived by those being measured, then there is the potential for misleading inferences to be made. The results of this study revealed that there were some problems related to the four steps of the response process and this provided the basis for instrument modification for the SCI population which may improve interpretation of results and decision-making by reflecting the perspectives of those measured.

There were a number of problems with the first step of the response process, question interpretation/ comprehension. The choice of words can have a major impact on question response by changing the substantive meaning of the question or eliciting different associations (Hippler & Schwarz, 1987). This was evident with the items regarding "clearing secretions" and "amount of pain". The level of literary comprehension of the word "secretions" was too high for some and caused a shift in focus to the word "lungs" which was associated with the ability to cough. The misunderstanding activated concepts that affected their response, which shifted the intended meaning of the item. Similarly, the necessity of the word "amount" in the item regarding pain became evident based on the responses of individuals that reported low levels or no pain.

The ability to retrieve pertinent information, the second step, then followed by judgement formation was the difficulty with the item regarding "spouse, lover or partner". Again the assumption by the respondents was that the question did not apply if they currently did not have a significant other in their life. Information that would be recalled to answer this item would require a reference period shift, which was not an option with the way the question was presented. Without the addition of an item to address satisfaction of not having a significant other, valuable information could be lost. A study evaluating a measure of quality of life in occupational therapy, revealed that the item most frequently chosen as contributing to quality of life for a sample of persons with spinal cord injury was the love of a significant other (Robnett & Gliner, 1995). Having a partner was among the factors that were mentioned when a sample of individuals three years post SCI, were asked what they felt would raise their QOL (Stensman, 1994). In addition, Kreuter et al. (1998) found that global quality of life ratings were significantly lower among single persons as compared to those individuals with SCI that were involved in a partner relationship.

In some cases, problems with the first and second steps of the response process, comprehension and retrieval, were linked. The way in which the items were understood did not permit the participants to recall any memory content with which to form a judgement. It became evident that the lack of information retrieval was due to the wording of the question. It was necessary to consider the key words in the items, which affected the ability of the participants to recall events applicable to an answer. With two items in particular, re-wording the item to eliminate the key words "age" and "God" allowed the participant to contemplate events relevant to these topics that were not previously considered.

In addition to problems with the four steps of the response process, there was the potential for the order of question presentation to influence participant's responses, particularly if cues were given that could affect information retrieval (Strack, 1992; Sudman et al., 1996). The data suggest that the participant's answers were not influenced substantially by previous questions. For example, when responding to the item referring to family health, it was possible that married participants, would not recall information pertaining to other members of their family, besides their spouse and children when asked this question. The intent of the question was to consider members of the family beyond spouse and children, particularly so that non-married individuals would also recognize the item as applicable to their situation. The question pertaining to family preceded the items regarding spouse and children and it may be that this helped individuals recognize family in a broader perspective.

Also with regard to order effects, previous research with the QLI has found that asking participants about satisfaction with their sex life before asking about satisfaction with their spouse or partner, avoided redundancy about the sexual aspect of the partner relationship (Warnecke et al., 1996). In this study, even though the order remained as per the original QLI, with the spouse item first, all participants focused on aspects other than sex when discussing their relationships. The companionship, emotional support and ability to communicate were clearly the most salient aspects of their relationships, only one participant mentioned sex. Even when discussing the item pertaining to their sex life, the emotional aspects were discussed as well as the physical capabilities. The participants were very communicative and reported that they were not embarrassed when responding to the questions, which would make it unlikely that the lack of conversation about sex when referring to the partner relationship was due to discomfort. For individuals with SCI, the focus of a relationship may have changed as reflected in the results of Kreuter et al. (1996) who found that after spinal cord injury, a satisfying sexual life and relationship is more dependent on psychosocial rather than physical factors.

The additional item referring to the ability to have children was deliberately placed after the item about sex life and not with the items about family and children. There was potential for the participants to focus on the parenting aspects of having children if the sequence emphasized a perceived episodic relationship between family and children. The intent of the item was to elicit thoughts about their biological abilities to have children and it was thought that the previous item about sex life would assist the participant with their interpretation. The participants' interpretations of the item, which clearly emphasized the physical aspects of creating a new life, suggest that the item order may have facilitated their comprehension of the question.

To determine if the items of the QLI captured the essence of QOL for individuals with SCI, the participants were asked to comment as to whether items should be added or deleted. The results indicate that most of the individuals were satisfied with the range of items presented in the QLI and no one commented regarding the deletion of any one item. There were some suggestions for additional items, some specific to individuals with SCI, and some that reflected more general aspects of life. One of the aspects specific to SCI that was suggested as an additional item, residential or attendant care, was found to be described by the majority of participants within the context of the "health care" item. There were two general aspects of life, vacation and stress that were also suggested for addition to the QLI. Both of these issues were discussed by a few of the participants. Vacation was intended to be considered within the "things you do for fun" item and was explored in that item as well as a few other items. The issue of stress was conceptualized as part of the item pertaining to worries and two participants did mention stress. Since these life aspects were discussed, although not by all, and they were not examined in greater detail, it would be premature to add either item to the QLI.

## Structural Component

Two aspects of the structure of the QLI were addressed in the present study. The domains of the QLI were examined as part of a free sort task of Phase 1 and examined using factor analysis as part of Phase 2. The scoring model was evaluated with the ranking task and the examination of relationships between total and section scores as part of Phase 1. The hypotheses with respect to the structure of the domains and scoring model of the QLI were not supported and will be discussed in turn.

### *QLI Domains*

The ranking of the domains by the participants in Phase 1 were analyzed by determining the proportion of pairings within and between domains and also by evaluating the patterns of the groupings descriptively. Although the proportion of pairings within each domain was higher than between the domains, the values were too low to lend support to the existing domain structure of the QLI. The variety of the participant groupings evident in Phase 1 of the study could be related to the difficulty encountered when participants are asked to rank more than five or six items (Bradburn & Sudman, 1979). Although based on a small sample size, the results of the factor analysis from Phase 2 seem to indicate that a four domain structure may not best conceptualize the situation of individuals with spinal cord injury. Inconsistencies in the structure were noted when comparing the groupings of the items by the participants in Phase 1 and the five factors identified in Phase 2. The implication of these results is that the use of subscores for the four domains of the QLI should not be applied to individuals with spinal cord injury without further study. However, the pattern of groupings in both phases of the study do give some insight to the relationships among different life aspects and how these may be conceptualized as dimensions of QOL for persons with SCI. The connection between life aspects and the identification of domains may provide some guidance for interventions to enhance QOL.

With many of the items in the health and functioning domain, the participants from Phase 1 recognized the similarity among some of the items, which was evident in their groupings. The grouping of one item, the ability to have children, did not seem to correspond with the way in which participants discussed this item during the interviews. Many ranked this item with other items from the family domain, yet during their conversations about this aspect of their lives, the focus was on the physical functioning associated with the biology of having children. The results of the factor analysis supported the interview discussions of Phase 1, in that the ability to have children was more closely related to other items reflecting health. This experiential split between the biological and social concerns associated with sexual activity is evident in the literature. Sexual functioning after spinal cord injury often reflects two distinct areas, sexuality, encompassing the physical and psychological aspects of a satisfying sexual relationship and reproductive/ fertility issues (Hart et al., 1996; Siösteen et al., 1990b; White et al., 1992; White et al., 1993). This study suggests that interventions aimed at determining and facilitating the ability to have children should consider aspects of biological function as well as the impact on family life and psychosocial functioning.

Another item, sex life, originally conceptualized as part of the health and functioning domain was not indicated as relating to other items in this domain. The participants in Phase 1 grouped this item most commonly with the item pertaining to their spouse, lover or partner, an item that is part of the family domain. The factor analysis revealed that this item was strongly related to other items that were part of the original psychosocial domain. The interviews from Phase 1 indicated a strong emphasis on the emotional and intimate relationship with their partner so the results from the factor analysis do not seem unrepresentative of their views. Research has shown that individuals with SCI do not focus on the health status of sexual functioning as defined by the level of injury, but that life satisfaction, self esteem, their partner's enjoyment and open communication will promote a satisfying sex life (Kreuter, 1996; Siösteen, 1990b). Contrary to the conceptualization of the original QLI, a satisfying sex life for individuals with spinal cord injury is not so much a health issue as a psychological issue and this should be considered in any counseling interventions. It is interesting to note that the items of sex life and the ability to have children were among the items with the lowest weighted scores indicating that these issues are considered very important but the participants were not satisfied with these life aspects. From a theoretical perspective, these items appear to represent the relationship between the disability level of the main pathway and the influence of psychosocial attributes.

The item pertaining to the "ability to take care of family responsibilities" which is part of the health and functioning domain of the original QLI, was divided into two categories in both phases of the study. In Phase 1, there was an even split between the categorization of the family responsibilities item within the health and functioning domain and the family domain. During the interviews of Phase 1, there were two separate issues that were raised, one centered on the individual's physical capabilities in relation to their responsibilities and the other, focused on their emotional and intellectual accountability. In Phase 2 this item loaded on two factors, one factor represented functioning and the other factor represented life circumstances that could limit activities. Family responsibilities would logically fit with the idea of functional independence. Qualitative QOL studies with rehabilitation clients and individuals with spinal cord injury have identified the issue of independence and maximizing potential with respect to doing as much as they were able to do without relying on others (Bach & McDaniel, 1993; Pain et al, 1998). Fulfilling family roles through appropriate responsibilities, whether physical or intellectual, could be viewed as part of independent functioning. Concerning the rehabilitation of functional abilities, it would be important to consider individual as well as family activities reflecting the disability and handicap levels of the theoretical framework.

For both phases of the study, there was some consistency in the groupings of the items, which were part of the original psychological and spiritual domain, with the exception of the item referring to faith in God. The lack of agreement among the participants of Phase 1 for the grouping of this item seems to reflect the view of Cella (1992) who describes spirituality as too distinct a domain to be considered a component of quality of life. However, it is noteworthy that other research has recognized spirituality as a separate domain in its own right and an important contributing factor to QOL (Donovan et al., 1989; Huebner et al., 1998; Robnett & Gliner, 1995; WHOQOL Group, 1995). The factor analysis results are somewhat confusing, as this item loaded on the factor that, for the most part represented health and wellness. For patients with cancer, it has been shown that as health deteriorates, spiritual issues become more important as determinants of QOL (Gotay, 1984). Spinal cord injury is not generally associated with deterioration unless one considers the secondary complications that continually threaten the health of the individual with SCI. The results of this study do not provide evidence to elucidate the relationship between health and spirituality therefore this is an area for further study potentially impacting the integrated theory of disablement and QOL.

The results of Phase 2 provide preliminary evidence that the domains of the QLI as originally conceptualized may be different for individuals with SCI. It is important to emphasize that the analysis was incomplete as some items were not included and the remaining items accounted for only 54.7 percent of the total variance. Thus, much of the variance is not explained by the factor structure presented. However, the domains represented in this factor structure are similar to the conceptualization of QOL by other authors (Hörnquist, 1989; WHOQOL Group, 1995; Wood-Dauphinee & Küchler, 1992; Zhan, 1992). The domains described in these related models are compared to the factor structure of this study and the original QLI in Table 5-1. Although there appears to be some overlap, there are unique contributions made by each of the models.

The factors identified in this study can be related to the modified disablement model of Verbrugge and Jette (1994). The first domain of happiness/ self-fulfillment appears to reflect the intra-individual factor of the model, which includes psychosocial attributes such as positive affect and emotional vigor. In comparison to the conceptualization of QOL by others, psychological components are common among all. Individuals with SCI have identified that attitude toward life significantly influences QOL (Boswell, 1998). This psychological variable was defined as "involving a state of mind that colors one's perception about themselves and life".

The domain described as family/ community would best fit within the extra-individual factors of the model, which includes external supports and social environment but is also related to the level of handicap, specifically social integration. The issue of relationships with family and others is not new to the conceptualization of QOL and has been identified by persons with SCI as significantly affecting their QOL (Bach & McDaniel, 1993; Warren et al., 1996). The results of this study show that the highest weighted items (Table 4-6) all represent this domain and indicate that these are very important life aspects, with which the participants are very satisfied. The items included within this domain go beyond the individualistic view of relationships to consider the well-being of the family. In the qualitative study of Pain et al. (1998), the

**Table 5-1** Parallels between the factor structure of this study, the domains of the original QLI and the conceptualization of QOL domains by other authors

| Five Factor Structure | QLI - Ferrans & Powers, 1992 | Hörnquist, 1989 | Wood-Dauphinee & Küchler, 1992 | WHOQOL, 1995 | Zhan, 1992 |
|---|---|---|---|---|---|
| Happiness/Self-Fulfillment | Psychological & Spiritual | Psychological | Psychological | Psychological | Self-Concept |
| Family & Community | Family | Social Structural | Interpersonal | Social Relationships | |
| Functional Independence | Health & Functioning | Behavioral/ Activity | | Level of Independence | |
| Life Circumstances | Social & Economic | Material | Socio-Economic | | Socio-Economic |
| Health & Well-Being | Health & Functioning | | | | Health functioning/ Physical Well-being |
| | | Biological | Somatic | Physical | |
| | | | | | Life Satisfaction |
| | Psychological & Spiritual | | Spiritual | Spiritual | |
| | | | | Environment | |

rehabilitation clients indicated that their own quality of life was related to their family's happiness and well-being.

The items represented within the independent functioning domain appear to span the disability and handicap levels of the main pathway of the model. When comparing the conceptualizations of QOL as presented in Table 5-1, the issue of functional independence is subsumed within the categories of general health, functioning and activity or else it is not recognized as a separate dimension. The concept of independence or maximizing potential which focused on doing as much as possible has been identified by individuals with SCI and other rehabilitation clients as an important category of QOL (Bach & McDaniel, 1993; Pain et al., 1998). For persons with SCI, the most commonly mentioned category was that of independence and the authors noted that this essential aspect should be reflected in instruments designed to measure QOL (Bach & McDaniel, 1993). The original QLI did not recognize independent functioning as a separate domain, but it seems that it may be an important consideration when evaluating the QOL for persons with SCI.

Most of the items of life circumstances appear to reflect the handicap level of the main pathway which emphasizes the difficulties encountered in doing activities of daily life such as a job (the major source to meet financial responsibilities) and recreation. Although the item of pain may best reflect the impairment level of the main pathway; its inclusion within this factor may represent a causal relationship with respect to the difficulties in carrying out activities of daily life. The item pertaining to family responsibilities, although retained as part of the functional independence domain, showed a strong affiliation to this category as well. The relationship between family responsibilities and the handicap level was discussed by some of the participants of Phase 1, however further study would be required before concluding that this item would better fit with the domain of life circumstances. As compared to other conceptualizations of QOL which primarily focus on the economic aspect, the notion of life circumstances presented here is somewhat distinct and may reflect issues and life challenges that are unique to persons with SCI.

The final domain, which has been labeled health and well-being, includes items that could be part of the disability and handicap levels and items that are better reflected as part of the psychosocial attributes as described within the intra-individual factors. Although the issue pertaining to the ability to have children has been studied within the context of sexuality (Hart et al., 1996; White et al., 1992; White et al., 1993), this author is unaware of any studies that have included this aspect as part of a study of QOL. The discussions by the participants of Phase 1 of this study have lent support to the importance of including this issue when considering QOL. The discussions also supported the inclusion of this topic as a health issue reflecting functional limitations. Further study is required to clarify the relationship of the apparent psychosocial variables within this domain, especially the item reflecting faith.

One of the difficulties in evaluating the possible domains of QOL for individuals with SCI was that there were a number of items that were not included in the analysis. The current wording of the items precludes a response from all participants, which reduced the size of the sample that could be included in the analysis. Two sets of items are complementary, such that a response to one item would mean the other item was not applicable. Perhaps a rewording of the item so that all respondents could report on the one issue would be better. For example, the items pertaining to "having/ not having a job" could be rephrased to ask the respondent about their "employment situation" and reference to demographic data about employment status would provide the frame of reference for the answer. The item referring to the satisfaction with children is difficult to rephrase. The item implies that the normative situation is to have offspring, which does not really reflect the diversity of situations within society. Given the importance of family relationships that has been emphasized in recent studies of QOL, perhaps the item should reflect the "satisfaction with family members" which would include children. Many persons with SCI are injured at an age when they would not likely have yet had children and the aspect of children that may be more important could be the reproductive capabilities. Therefore, rephrasing this item may not be inappropriate, however further evaluation in subsequent research would be required.

Despite the cautions for reviewing factors identified in this study, it does appear that these results in addition to recent research, supports the idea that the structure of domains for persons with SCI may reflect issues that are unique to their situation. The evaluations from Phases 1 and 2 of this study also have theoretical implications in recognizing the interdependent relations of specific life aspects from the perspective of the individual with spinal cord injury. This draws into question the analysis of QOL involving the separation of domains of life aspects. Would the use of domain subscores facilitate the planning and evaluation of interventions aimed at improving QOL or would a total score suffice? Perhaps the identification of domain scores would identify areas of treatment focus, however some significant life aspects could be overlooked if the categorization of domains requires a choice be made as to where any one life aspect would fit. This would be an area of further study, specifically within the context of clinical trials.

### ***Scoring Model***

The second structural component of validity investigated, the scoring model, also provided interesting and somewhat controversial results. The conceptualization of the scoring model of the QLI adheres to the individualistic ideology and therefore incorporates ratings of satisfaction and importance in determining the final score. The ranking data seem to indicate that the participants did not recognize the items within each domain with respect to a scoring continuum based on a decision incorporating the consideration of the satisfaction with and importance of the item. Although there was some indication that both satisfaction and importance were used, it appears that the salient factor for the decision process was the importance of the life aspect. One reason for this could be that the participants did not clearly understand the task. In an attempt to avoid leading the participant to consider either satisfaction or importance, the question was phrased so they were asked to consider the item as it "contributes to their determination of a good QOL". Perhaps this wording evoked a decision process that caused the participants to reflect primarily on the importance of the life aspects. Unfortunately, the investigator did not probe the participants to explain the decision process that they used when ranking the items.

The correlations between the weighted total and non-weighted section scores from Phase 1 seemed to indicate, at first, that the inclusion of the importance ratings offered no more information than multiplying the data by a constant. Considering that the overall variance of the importance scores was low, this seemed to be a plausible explanation. However, the removal of the outlier data point did indicate that the importance score was making some contribution. Considering the small sample, the correlations between the weighted and non-weighted scores for the data from Phase 2 were also analyzed. Similarly, there was a high correlation between the weighted total QLI score and the non-weighted satisfaction score, and a moderate correlation between the weighted total QLI score and the non-weighted importance score. Before concluding that the importance scoring is redundant, it is necessary to consider how inferences are to be made from the quality of life scores.

If the results are to be interpreted without reference to the distribution of scores of others, then an absolute statement is made (Cronbach, 1971). Individual evaluation of quality of life should center on absolute interpretation when the purpose of measurement focuses on treatment planning and outcome evaluation. Little may be added by reporting where an individual ranks in relation to others of the group, a comparative assessment, particularly in the instance of QOL. Two individuals may have the same overall score on the test, however the domain subscores may reveal that one person has issues that focus on more physical aspects of life, whereas the other person may have difficulty with psychosocial issues. Does the lower score of one individual as compared to another indicate lower QOL? If QOL is viewed as a continuum such that a higher score is better, then the answer is yes. However, if the scores are viewed as reflecting the perceptions of an individual then the use of comparisons on a continuum is less meaningful. Decisions regarding appropriate interventions to enhance QOL would be made on the basis of the individual's perception of their QOL with specific life aspects, not based on a comparative assessment. There is the potential for the importance data to be useful, particularly in considering the client centered philosophy of treatment.

Measuring importance of various elements of QOL has received much support in the literature. It has been argued that "quality of life may not be properly characterized unless patients are also invited to rate the importance of the problems" (Gill & Feinstein, 1994). In two separate studies of individuals with rheumatoid arthritis, the results indicated that the meaning of or satisfaction with specific abilities was different depending on what was considered most important by the individual (Blalock et al., 1992; Locker, 1983). When defining QOL, separate studies with samples of rehabilitation clients and persons with SCI noted that the degree of importance of specific life domains was unique to individuals (Boswell et al., 1998; Pain et al., 1998). The inclusion of the importance rating would be beneficial when considering treatment interventions. Although domain scores can indicate an area of concern, it would be the item evaluation that would direct care. If an individual has the same ranking of dissatisfaction for separate items but one item has been rated as more important, then logic would dictate that treatment focus on the more important aspect of life. This forces the consideration of the scaling of the importance section. It was noted that the overall variance of importance scores was low (scores mostly reflected high importance) and in some instances, such as the family domain subscore, there was no variance at all. It may be that the anchor phrasing in which the low end of the scale indicates "no importance" forces the choices to be predominantly in one direction. Perhaps the discrimination of the levels of importance would be facilitated with an anchor phrase that did not have such negative connotation, however this would require further investigation.

Evaluating the scoring model is important, even when the procedures logically follow from a theoretical framework. However, changes to the scoring, especially if based on a small number of individuals, could affect the inferences that can be made from the results and there is the potential to lose valuable information. Rather than change the scoring procedures as outlined in the QLI, the results of this study suggest the information from the two parts could be used separately. The satisfaction scores alone can give an accurate picture of QOL as indicated by the correlations of the weighted total and non-weighted section scores, whereas the importance scores could be evaluated to indicate areas for further study or intervention as implied by the results of the ranking exercise.

### External Component

The external component of validity seeks to test the hypothesized relationships between the test scores and the scores of other measurements that are implicit in the theory of the construct being studied (Messick, 1995; Nunnally & Bernstein, 1994). Within this study the relationships that were hypothesized were based on the theory of disablement which includes quality of life (Verbrugge & Jette, 1994). Of the hypothesized relationships, three of the five were supported by the data.

The literature to date is fairly consistent with respect to the relationship between impairment, abnormalities of body systems, and quality of life for persons with spinal cord injury. Often the level of impairment is represented by the level of lesion, in other words, quality of life scores are compared between persons with paraplegia and quadriplegia which sometimes includes subgroups of complete and incomplete injuries. Many studies have found that there is no significant difference in the QOL scores between groups based on level of injury (Cushman & Hasset, 1992; Decker & Schulz, 1985; McColl & Rosenthal, 1994; Nieves et al., 1991; Siösteen et al., 1990;). The work of Clayton and Chubon (1994) contradicts these results as they found that there was a significant difference between persons with paraplegia and quadriplegia. Although it may be that the samples or the methods of severity classification were somewhat different, the controversial results are possibly due to the approach to the assessment of QOL. Unlike the other studies, the measure of QOL was developed specifically for persons with SCI (Chubon, 1987) and thus may be more sensitive to detecting differences between groups. A meta-analysis of quality of life studies has indicated that severity of injury is associated with QOL, such that QOL is reduced for those with more severe injury (Evans et al., 1994). None of the above studies interpreted the results with respect to a model of disablement and the meta-analysis did not distinguish between measures at the level of impairment and disability.

Only Fuhrer et al. (1992) specifically evaluated the relationships with respect to the WHO model of disablement. Also the level of impairment was not a dichotomous classification, but rather physical evaluation was used to determine the ASIA total motor index score. The correlation between the measure of quality of life and the AISA motor score was –0.036, which is very similar to the results of this study, which also used the ASIA motor score to represent impairment. A recent meta-analysis which specifically analyzed the effects of the three levels of disablement found that the relationship between impairment and QOL is weak with a mean correlation of -0.05 (Dijkers, 1997). Given these results, it is not surprising the hypothesis concerning the relationship between the level of impairment and the scores of the QLI was supported. This does not indicate that the items representing the level of impairment should not be included as part of a measure of QOL. Pain, which represents the level of impairment, has been shown to significantly influence QOL for persons with SCI (Lundqvist et al., 1991; Stensman, 1994). In addition, the item of pain in the QLI was among the lowest weighted items by the participants of this study indicating that it is an aspect considered to be important but rated low in terms of satisfaction.

The hypothesis concerning the relationship of QOL with the level of disability was not supported. Although it was expected that the association between QOL and disability would be stronger than the association with impairment, it was still expected that the results would be non-significant. Documented research has not demonstrated consistent results. Significant correlations have been documented between QOL and the Barthel Index (0.66), the Katz ADL scale (-0.24), and a self report of the amount of assistance needed with activities of daily living (-0.35) (Coyle et al., 1994; Decker & Schulz, 1985; Dunnum, 1990). The results of other studies contradict these findings. Quality of life was not related to the FIM motor subscale (0.07), the total FIM score or a self report of ADL dependence (correlations not reported) (Fuhrer et al., 1992; McColl & Rosenthal, 1994; Stensman, 1994).

Except for Fuhrer et al. (1992) and McColl and Rosenthal (1994), all the measures of disability used in these studies were different. All the instruments used to measure QOL also differed, except for Decker and Schulz (1985) and Fuhrer et al. (1992) who used the LSIA-A, and none of the QOL measures used were validated for persons with spinal cord injury. With the exception of Fuhrer et al. (1992), none of the research had specific hypothesis relating to the WHO model of disablement. The meta-analysis of Dijkers (1997) has shown that the association (mean r = -0.21) between QOL and disability is weak to moderately strong and not found consistently. Despite the advantages of meta-analysis in addressing problems of small sample size, design differences and the varying characteristics of samples, future research of QOL after SCI needs to include valid, reliable and uniform measurements (Dijkers, 1997; Evans et al., 1994).

Similar to Fuhrer et al. (1992) this study also used the FIM to evaluate disability and the descriptive results were similar (mean score of 59.5 as compared to 62.58 for this study), however the correlations between disability and QOL were quite different (0.071 as compared to 0.20 for this study). If one considers the causal flow of the model of disablement, it would be expected that disability would be more strongly related to QOL than impairment and this was the case for this study. Despite a significant result, the magnitude of the correlation was low such that much of the variability of QOL is explained by other factors.

The results of this study indicate a strong relationship between QOL and overall handicap as measured by the Reintegration to Normal Living Index. Although most studies have evaluated specific aspects of handicap separately, the conclusions are fairly consistent in that lesser handicap is associated with greater quality of life. The average correlation from the meta-analysis of Dijkers (1997) was –0.34 with the range of mean correlations being –0.17 to –0.49 for the subcategories of handicap. The components of handicap that are most commonly assessed regarding a relationship to QOL include occupation, correlations ranging from 0.23 to 0.35, mobility (0.21 to 0.53) and social integration (0.12 to 0.51) (Clayton & Chubon, 1994; Decker & Schulz, 1985; Fuhrer et al., 1992; Nosek et al., 1995; Siösteen et al., 1990; Vogel et al., 1998). Social support which would be an aspect of social integration has also been shown to relate strongly to QOL with correlations ranging from 0.33 to 0.75 (Decker & Schulz, 1985; McColl & Rosenthal, 1994; Rintala et al., 1992). Although Fuhrer et al. (1992) and Nosek et al. (1995) and Vogel et al. (1998) specifically used an instrument designed to measure handicap, only the latter study evaluated overall handicap with QOL ($r = 0.39$).

The Reintegration to Normal Living Index has been used as a measure of overall handicap for persons with spinal cord injury (Daverat et al., 1995). However, only in the paper describing the development of the instrument is the relationship between QOL and the RNL mentioned ($r = 0.68$) which is very similar to the correlation found in this study (Wood-Dauphinee et al., 1988). The hypothesis regarding the relationship of QOL with overall handicap has been supported and the progressively stronger relationships evident gives support to the linear representation of impairment, disability and handicap within the model as well as the placement of QOL at the end of this continuum. The variety of results of other studies examining specific aspects of handicap indicates that to understand the effect of handicap on QOL, further study is required. Also, the range of correlations demonstrated indicate the need to use reliable and valid measures that focus on handicap.

The intraindividual factors of self esteem and locus of control were expected to be significantly related to QOL. In this study the participants demonstrated a relatively high level of self-esteem and this was related to the perception of a better QOL which supported the hypothesis. The average score for self-esteem in this study as measured by Rosenberg's Self-Esteem Scale (31.29) is similar to other studies of individuals with spinal cord injuries that also used the same scale (range of average scores: 28.97 – 32.11) (Coyle et al., 1994; Hancock et al., 1993; Piazza et al., 1991). The impact of self-esteem on coping, adjustment and hope has been studied and results generally show a strong positive association between these variables which theoretically would be related to QOL (Koehler, 1989; Piazza et al., 1991; Van Den Bout et al., 1988). Although not studied within a framework of disablement, Coyle et al. (1994) found a significant correlation between self-esteem and life satisfaction ($r = 0.65$), a result almost identical to the present study.

The participants also showed a tendency for an internal locus of control, indicating they perceive themselves as being in charge of their lives, although this was not shown to be associated with QOL as expected. Research involving persons with SCI has produced contradictory results. Some authors have noted low perceived or external locus of control (Boschen, 1990; Fuhrer et al., 1992; Hancock et al., 1993) while others have found a more internally oriented or higher perception of control (Decker & Schulz, 1985; Ferington, 1986; Schulz & Decker, 1985). It is difficult to compare results when different measures were used. Only Ferington (1986) used Rotter's I-E Scale and the results were almost identical to this study with a mean score of 8.63 and a standard deviation of 3.33.

With respect to the psychosocial variables as a part of the model of disablement, the results are not clear especially with respect to locus of control. Perhaps individuals with spinal cord injury view control differently or perhaps the instrument used to measure locus of control did not tap into the issues of concern for persons with spinal cord injury. It is interesting to note that control was an issue discussed by the participants in the study of Bach and McDaniel (1993) which was reflected as an "ability to make the best of what they had and to do with what they had". Similarly, Yoshida (1993) discovered that the integration of the "disabled self" in the reconstruction of identity for persons with spinal cord injury includes an understanding or acceptance of their limitations. Perhaps the idea that locus of control is stable, as suggested by Rotter (1966), does not reflect the situation for persons with SCI, but rather the pendular model proposed by Yoshida (1993) may be a more accurate representation of what happens. Only longitudinal study can elucidate this issue. Perhaps the results of this study argue that there is a reality of control and a belief of control and these aspects may be differentially related to QOL. These results do not indicate that the QLI is an invalid measure but rather points to further study of the relationships of the intraindividual factors with QOL in order to provide conceptual clarity to the model of disablement.

### Prediction of QOL

The model of disablement was being tested to the extent that variables at the level of handicap are most strongly related to QOL and therefore should be the best predictors. In attempting to address the issue of longitudinal prediction of QOL, this study found that none of the variables selected from the database were significant predictors of QOL. There are a number of possible explanations. Although the data for the dependent variable was slightly skewed positively, violating the assumption of a normal distribution, this assumption is not essential for useful inference (Darlington, 1990). Also the restricted variance of the dependent variable, the QLI total score, and the walk and employment variables would contribute to low correlation coefficients and therefore poor prediction. In addition, three independent variables were dichotomous and the maximum correlations expected would be low. These factors in combination with relatively small sample, although the size did exceed the 5:1 ratio for subjects to variables, would limit the ability to successfully predict QOL.

The variables used for prediction in this study were limiting in that only variables that existed in the database could be selected. The majority of variables within the database were measured at the impairment and disability level. Only employment after injury could be identified at the handicap level, a change in a normal social role that would be a consequence of the SCI. Cross-sectional research has indicated that the best predictors of QOL are subjective variables such as perceived control, social/emotional support, self esteem, leisure satisfaction, perceived health, social and psychological functioning (Coyle et al., 1994; Fuhrer et al., 1992; McColl & Rosenthal, 1994; Post et al., 1998; Schulz & Decker, 1985; Vogel et al., 1998). This does not preclude the effect of impairment and disability on QOL as some authors have noted that variables such as pain, urinary tract infections and dependency are significant predictors of life satisfaction (Krause & Dawis, 1992; Vogel et al., 1998).

Only two authors specifically evaluated the prediction of QOL within the framework of the model of disablement (Fuhrer et al., 1992; Vogel et al., 1998). Using the Craig Handicap Assessment and Recording Technique (Whiteneck et al., 1992), both studies found that despite significant correlations with life satisfaction, neither the total CHART score nor the subscales were significant predictors of life satisfaction. The results of Vogel et al (1998) should be viewed with caution as the subject to variable ratio was less than 5:1. Although not studied with respect to a model of disablement, Krause and Dawis (1992) found that employment status was a significant concurrent and longitudinal predictor of economic satisfaction. It becomes apparent that longitudinal studies are lacking and given the results of this study, it seems that any future longitudinal research should ensure that the subjective variables of psychological and social functioning are included.

### Generalizability

For all phases of the study, there is the assumption that the participants will be representative of the general spinal cord injured population in Northern Alberta. Unfortunately few statistics are available for the Alberta population. The samples were limited to those who voluntarily responded to the request for participation. There is the possibility that the characteristics of those that chose not to respond are different form those that did participate, specifically with respect to their perception of their QOL. Generalizability beyond the sample can only be determined by comparison of the demographic characteristics of the study participants with those in other areas. In comparing the characteristics of the Phase 2 and Phase 3 samples to the characteristics of the subjects in the published literature, they were similar with a few exceptions. The Phase 2 sample was slightly older and had a longer duration of injury and the Phase 3 sample had a slightly higher percentage of persons employed. These differences need to be taken into consideration when interpreting results.

## Limitations

Specific to the procedures of Phase 1, the ability of the participants to articulate their thoughts and provide rich descriptive information could have limited the evaluation of the questionnaire items. To reduce this problem, some of the participants were individuals with whom the investigator had personal knowledge of their abilities and willingness to provide articulate information. In addition, to avoid the possibility that the interviewer communicated her expectations to the participants, a consistent list of interview probes was used. With an insider's perspective about issues related to having a SCI, the interviewer may have missed the exploration of unclear answers by making incorrect assumptions as to the intended meaning of the participant. Careful listening and paraphrasing of the participant's answers was designed to minimize this problem. The potential of underreporting due to anxiety about the topics of discussion was not evident in this study. Interviews were conducted in a location chosen by the participants and all reported that, for the most part, they did not feel uncomfortable in answering the questions. Although more anonymous self-administered methods are more likely to encourage fuller response to sensitive questions (Hippler & Schwarz, 1987), the perceived connection with the interviewer based on her professional and personal background likely facilitated the discussions in this study. The QLI is designed so that it can be administered in either an interview or a self-report format depending on the situation. The presence of the tape recorder could also have affected responses, although this is unlikely as evidence suggests that virtually all respondents almost immediately forget the presence of the machine (Sudman et al., 1996). In this study, none of the participants seemed to take notice of the tape recorder.

For Phase 2, the results are limited by the accuracy of the instruments used. For this reason, valid and reliable instruments were selected for correlation with the QLI. Only one rater was used for the measurement requiring rater assessment, the ASIA total motor index. All of the other measures involved self-reports by the participants. There was the potential that the responses to the questionnaires be affected by social desirability. Although this was not examined empirically, the participants in this study did demonstrate a fairly large range of scores and the investigator noticed that individuals responded quickly to items, indicating they did not stop to consider the desired response.

As part of this phase, the factor analysis was limited by a small sample size and the incomplete analysis of all of the items in the QLI. This has been discussed, with suggestions for possible changes prior to additional research.

Finally, the largest limitation for Phase 3 of the study related to the use of variables from an existing database. To test the model adequately, it would have been preferable to have sufficient variables using continuous data that represent the levels of impairment, disability and handicap as well as subjective measures of psychosocial aspects. In addition, when using an existing database, the investigator can never be sure of the reliability with which the data were collected. It would also be more appropriate to evaluate the relationships in a longitudinal manner as opposed to the non-concurrent design used in the present study.

Another limitation that may have affected all phases of the study was related to the assumption regarding reliability. The SCI version of the QLI as proposed by the test developers had not been tested for reliability and it was assumed that the reliability estimates obtained by the developers with graduate students and hemodialysis patients would be appropriate for the SCI population. Given the potential for modifications to the instrument it was decided that validity would be tested first.

## Implications for Rehabilitation

Previous literature as well as this study suggests that quality of life is multidimensional and consideration of these aspects within rehabilitation should be recognized. The emphasis of restoring independent physical function may not completely address the factors that influence successful rehabilitation. The model of disablement indicates both social and environmental factors that could mediate the main pathway of impairment, disability and handicap. For example, from this study there is an implied relationship between social support and QOL, as demonstrated by the life aspects representing relationships that were given the highest ratings. Therapists could make specific efforts to involve the person's family and friends in aspects of their rehabilitation as well as to recognize the potential of the themselves as a therapist, to be a source of positive social support. Similarly self-esteem, also strongly related to QOL, could be enhanced within the interactions of the therapist and client as well as through family education which emphasizes the clients capabilities and strengths.

Although further examination of the QLI may be necessary, the use of the QLI within SCI rehabilitation shows promise. In particular, clinicians can use QOL assessment at discharge and follow-up to identify aspects that are of greatest concern to individuals with SCI. The baseline data can then provide the basis for evaluating and planning interventions designed to improve QOL. Interventions aimed at issues that could enhance the reintegration into the community would particularly impact QOL. Specific to this study, some of the life aspects, which had the lowest weighted scores such as pain, sex life and the ability to have children, could be addressed within rehabilitation and with adequate follow-up. Through the use of QOL ratings the client could become a partner in rehabilitation helping to identify their own problems and plan possible solutions.

## Future Research

Although most of the hypotheses were supported, further evaluation of the modified QLI is necessary which should include reliability assessment. The results with respect to the domains and scoring model have serious implications for the inferences that can be made from the scores. The relationship between the claculation of satisfaction and importance needs to be evaluated further and the domains of QOL for individuals with SCI should be clear before any subscale scores are used. The relationship between the handicap level and mediating psychosocial variables could be studied longitudinally to further clarify the relationships to subcategories of handicap and to determine how these aspects change in their relationship to QOL over time.

Since few studies have used measures of QOL that have been validated with persons with SCI, it would be interesting, after further evaluation of the QLI, to determine if replication produces similar results. The prediction of QOL from prospectively collected data needs further study, which could have implications for the planning of follow-up interventions after discharge from rehabilitation.

## Conclusions

In conclusion, the focus of validation within this study has been to evaluate the issue concerning the confidence, with which inferences can be made, a prerequisite to further study of the prediction of QOL. It was necessary to demonstrate that the items within the measure of QOL reflected the perspective of the individuals about whom decisions would be made. Few measures that evaluate a subjective construct have included an empirical evaluation of the item content with consideration of the point of view of the individuals to which the measurement will be applied. In addition, the perspectives of the individuals have not usually been examined with respect to a guiding theoretical framework. Therefore, this study evaluated the response processes with which the participants considered the items of the QLI. To the extent that the participants of this study are representative, modifications to the QLI items represent the opinions of individuals with spinal cord injury.

In addition, the validity has encompassed the evaluation of the domains of the QOL construct within the QLI as well as the scoring model. The evaluation of the domains or structure of the measurement contemplated the input from the participants in addition to the statistical evaluation. The investigation of the scoring model considered the application of the importance rating to provide a weighted score reflecting the individual nature of the subjective construct of QOL. Although the hypotheses were not supported, implications for the use of domain subscores and weighted scores are provided although substantial changes are not warranted without further study with a larger sample. The current study has contributed but a first step to encourage appropriate inferences from a measure that has been critically analyzed in terms of a specific population. Further validation with a larger sample using the modified version with the re-worded items is required prior to widespread acceptance of this measure of QOL for individuals with spinal cord injury.

Finally, successful prediction of QOL was not possible particularly considering the limitations of the data. More useful results would be evident if this research was carried out in a longitudinal manner with considerations of the level of data and the validity of the instruments. However, from a theoretical standpoint, these results suggest that the expansion of the theory of disablement to encompass quality of life needs to consider the interaction of the disablement process with individual psychosocial attributes and external environmental factors. Longitudinal study that considers these interrelationships would provide valuable insight for potential predictive models and intervention strategies.

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## **Appendix A** Consent Form – Phase 1

Measurement of Quality of Life of Spinal Cord Injured Persons: A Validation Study

Investigators: L. May, PhD candidate, Rehabilitation Medicine
Dr. S. Warren, Professor, Rehabilitation Medicine
Dr. R. Burnham, Associate Professor, Medicine
Dr. J. Golec, Assistant Professor, Sociology
Dr. L. Liu, Associate Professor, Occupational Therapy
Dr. T. Maguire, Professor, Educational Psychology

Purpose: The purpose of this project is to find out if an instrument that measures quality of life really does what it is supposed to. To do this, we need to find out if the instrument contains items that mean something to people who have spinal cord injuries. During an interview with the researcher at a place you choose, you will be asked to answer the questions in the instrument and tell her what led you to that answer. You will also be asked to sort out some cards with the questions on them in an order that makes sense to you. The interview will take about two hours and some parts will be audiotaped.

Consent: I, ________________________, (please print) agree to participate in the above named project which has been completely described to me. I understand that my participation is voluntary and I may withdraw from the study at any time without any effects on my present or future care. I may refuse to answer any questions if I so choose. I realize that I may not necessarily benefit from the study.

I understand that all information will be kept confidential. My name will not appear on any questionnaires, only an identifying code number. Audiotapes will be identified with a code number only. My name will not be associated with anything written about this project as only summary information will be presented.

All the questions I had about this project have been answered. I understand that I may call Laura May at 492 - 7499 or Dr. Sharon Warren at 492 - 7856, if I have any further questions.

I have read and understood the information stated above and I sign this consent form willingly. I will receive a copy of the consent form for my records.

________________________ ________________________

Participant's Signature Date

________________________ ________________________

Investigator's Signature Date

## **Appendix B** QLI Version Used in Phase 1

Ferrans and Powers
### Quality of Life Index
### Spinal Cord Injured/ Quadriplegic Version

Part 1: For each of the following, please choose the answer that best describes **how satisfied** you are with that area of your life. Please mark your answer by circling the number. There are no right or wrong answers.

Response Categories:

| | |
|---|---|
| A | Question not relevant (does not apply) |
| B | Could not answer this question (didn't understand it) |
| C | Refused to answer |
| D | Missing data |

**1** **2** **3** **4** **5** **6**

**Not at all Satisfied** … **Very Satisfied**

**HOW SATISFIED ARE YOU WITH:**

| | | | | | | | | | | |
|---|---|---|---|---|---|---|---|---|---|---|
| 1. Your health? | 1 | 2 | 3 | 4 | 5 | 6 | A | B | C | D |
| 2. The health care you are receiving? | 1 | 2 | 3 | 4 | 5 | 6 | A | B | C | D |
| 3. The amount of pain that you have? | 1 | 2 | 3 | 4 | 5 | 6 | A | B | C | D |
| 4. Your ability to clear secretions from your lungs? | 1 | 2 | 3 | 4 | 5 | 6 | A | B | C | D |
| 5. Your ability to take care of yourself without help? | 1 | 2 | 3 | 4 | 5 | 6 | A | B | C | D |
| 6. Your ability to go places outside your home? | 1 | 2 | 3 | 4 | 5 | 6 | A | B | C | D |
| 7. The amount of energy you have for everyday activities? | 1 | 2 | 3 | 4 | 5 | 6 | A | B | C | D |

**HOW SATISFIED ARE YOU WITH:**

| | | |
|---|---|---|
| 8. The amount of control you have over your life? | 1 2 3 4 5 6 | A B C D |
| 9. Your chances of living to the age you would like? | 1 2 3 4 5 6 | A B C D |
| 10. Your family's health? | 1 2 3 4 5 6 | A B C D |
| 11. Your children? | 1 2 3 4 5 6 | A B C D |
| 12. Your family's happiness? | 1 2 3 4 5 6 | A B C D |
| 13. Your spouse, lover or partner? | 1 2 3 4 5 6 | A B C D |
| 14. Your sex life? | 1 2 3 4 5 6 | A B C D |
| 15. Your ability to have children? | 1 2 3 4 5 6 | A B C D |
| 16. Your friends? | 1 2 3 4 5 6 | A B C D |
| 17. The emotional support you get from your family? | 1 2 3 4 5 6 | A B C D |
| 18. The emotional support you get from people other than your family? | 1 2 3 4 5 6 | A B C D |
| 19. Your ability to take care of family responsibilities? | 1 2 3 4 5 6 | A B C D |
| 20. How useful you are to others? | 1 2 3 4 5 6 | A B C D |
| 21. The amount of worries in your life? | 1 2 3 4 5 6 | A B C D |
| 22. Your neighborhood? | 1 2 3 4 5 6 | A B C D |
| 23. Your home, apartment, or place where you live? | 1 2 3 4 5 6 | A B C D |
| 24. Your job (if employed)? | 1 2 3 4 5 6 | A B C D |
| 25. Not having a job (if unemployed, retired, or disabled)? | 1 2 3 4 5 6 | A B C D |

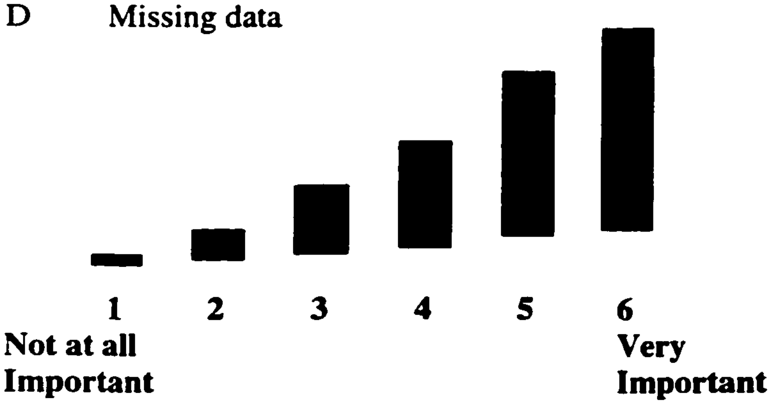
**HOW SATISFIED ARE YOU WITH:**

| | | |
|---|---|---|
| 26. Your education? | 1 2 3 4 5 6 | A B C D |
| 27. How well you can take care of your financial needs? | 1 2 3 4 5 6 | A B C D |
| 28. The things you do for fun? | 1 2 3 4 5 6 | A B C D |
| 29. Your chances for a happy future? | 1 2 3 4 5 6 | A B C D |
| 30. Your peace of mind? | 1 2 3 4 5 6 | A B C D |
| 31. Your faith in God? | 1 2 3 4 5 6 | A B C D |
| 32. Your achievement of personal goals? | 1 2 3 4 5 6 | A B C D |
| 33. Your happiness in general? | 1 2 3 4 5 6 | A B C D |
| 34. Your life in general? | 1 2 3 4 5 6 | A B C D |
| 35. Your personal appearance? | 1 2 3 4 5 6 | A B C D |
| 36. Yourself in general? | 1 2 3 4 5 6 | A B C D |

Part 2: For each of the following, please choose the answer that best describes **how important** that area of life is to you. Please mark your answer by circling the number. There are no right or wrong answers.

Response Categories:

| | |
|---|---|
| A | Question not relevant (does not apply) |
| B | Could not answer this question (didn't understand it) |
| C | Refused to answer |
| D | Missing data |



**HOW IMPORTANT TO YOU IS:**

| | | | | | | | | | | |
|---|---|---|---|---|---|---|---|---|---|---|
| 1. Your health? | 1 | 2 | 3 | 4 | 5 | 6 | A | B | C | D |
| 2. Your health care? | 1 | 2 | 3 | 4 | 5 | 6 | A | B | C | D |
| 3. Having no pain? | 1 | 2 | 3 | 4 | 5 | 6 | A | B | C | D |
| 4. Being able to clear secretions from your lungs? | 1 | 2 | 3 | 4 | 5 | 6 | A | B | C | D |
| 5. Taking care of yourself without help? | 1 | 2 | 3 | 4 | 5 | 6 | A | B | C | D |
| 6. Being able to go places outside your home? | 1 | 2 | 3 | 4 | 5 | 6 | A | B | C | D |
| 7. Having enough energy for everyday activities? | 1 | 2 | 3 | 4 | 5 | 6 | A | B | C | D |
| 8. Having control over your life? | 1 | 2 | 3 | 4 | 5 | 6 | A | B | C | D |
| 9. Living to the age you would like? | 1 | 2 | 3 | 4 | 5 | 6 | A | B | C | D |
| 10. Your family's health? | 1 | 2 | 3 | 4 | 5 | 6 | A | B | C | D |

**HOW IMPORTANT TO YOU IS:**

11. Your children? 1 2 3 4 5 6 A B C D

12. Your family's happiness? 1 2 3 4 5 6 A B C D

13. Your spouse, lover or partner? 1 2 3 4 5 6 A B C D

14. Your sex life? 1 2 3 4 5 6 A B C D

15. Being able to have children? 1 2 3 4 5 6 A B C D

16. Your friends? 1 2 3 4 5 6 A B C D

17. The emotional support you get from your family? 1 2 3 4 5 6 A B C D

18. The emotional support you get from people other than your family? 1 2 3 4 5 6 A B C D

19. Taking care of family responsibilities? 1 2 3 4 5 6 A B C D

20. Being useful to others? 1 2 3 4 5 6 A B C D

21. Having no worries? 1 2 3 4 5 6 A B C D

22. Your neighborhood? 1 2 3 4 5 6 A B C D

23. Your home, apartment, or place where you live? 1 2 3 4 5 6 A B C D

24. Your job (if employed)? 1 2 3 4 5 6 A B C D

25. Having a job (if unemployed, retired, or disabled)? 1 2 3 4 5 6 A B C D

26. Your education? 1 2 3 4 5 6 A B C D

27. Being able to take care of your financial needs? 1 2 3 4 5 6 A B C D

28. Doing things for fun? 1 2 3 4 5 6 A B C D

## HOW IMPORTANT TO YOU IS:

| | | |
|---|---|---|
| 29. Having a happy future? | 1 2 3 4 5 6 | A B C D |
| 30. Peace of mind? | 1 2 3 4 5 6 | A B C D |
| 31. Your faith in God? | 1 2 3 4 5 6 | A B C D |
| 32. Achieving of personal goals? | 1 2 3 4 5 6 | A B C D |
| 33. Your happiness in general? | 1 2 3 4 5 6 | A B C D |
| 34. Being satisfied with life? | 1 2 3 4 5 6 | A B C D |
| 35. Your personal appearance? | 1 2 3 4 5 6 | A B C D |
| 36. Are you to yourself? | 1 2 3 4 5 6 | A B C D |

## **Appendix C** Demographic Information Questionnaire

ID#____________
Age:
Level of Injury:
Complete/ Incomplete:
Age at Onset:
Employment Status:
  Full time
  Part time
  Unemployed

Attending Educational Institution:
  Full time
  Part time

Educational Status:
  Never Attended School
  Completed Some Elementary School
  Completed Elementary School
  Completed Some Junior High School
  Completed Junior High School
  Completed Some High School
  High School Diploma
  Trades Certificate/Diploma
  Some Post Secondary Education (University or College)
  College Certificate/ Diploma
  University Bachelor's Degree
  University Master's Degree
  University Doctoral Degree
  Unknown

Marital Status:
  Married or Common-law
  Separated
  Divorced
  Widowed
  Single

Accommodation:
  Own House or Condo
  Rent House/ Apartment/ Condo
  Long Term Care Facility
  Other

## **Appendix D** Interview Probes

| **Item** | **Questions** |
|---|---|
| 1. | Why do you feel that way?<br>In answering this question, what things about your health did you think about?<br>Are there any parts of your health you are satisfied / dissatisfied with?<br>What are they?<br>When you thought about how you felt about your health, did you compare it to how it was before, the health of other people like you, or something else? |
| 2. | Why do you feel that way?<br>What kinds of things do you think about when I say " the health care you receive"?<br>If dissatisfied: What are the things about your health care you are satisfied with? |
| 3. | When I asked the question, did you think about the pain you had today, the pain you had during the last week, or did you think about it in another way?<br>Could you describe your pain? |
| 4. | What do you think I mean by "the ability to clear secretions"?<br>If dissatisfied: How often is this a problem for you?<br>How do you manage this problem? |
| 5. | What does "without help" mean to you?<br>What comes to mind when you think of "taking care of yourself"? |
| 6 | What did you think about when answering this question?<br>What do you think I mean when I say "places outside your home"? |
| 7. | What do you think I mean by "amount of energy"?<br>What do the words "everyday activities" mean to you?<br>What are some of the things you do everyday?<br>Are the things you do different or the same as before your SCI?<br>How are they different?<br>Did you compare your everyday activities with what you used to do, with the activities of other people like you, or some other comparison? |
| 8. | What do you think I mean by "control"?<br>What are some of the things in your life that you can control?<br>What are some of the things you cannot control and that you are dissatisfied about?<br>Would you say you have more, less or the same control as before your SCI?<br>How has your control changed? |
| 9. | What did you think about when answering this question about the age you would like to live to? |

When thinking about your chances of living to the age you would like, did you compare this with your expectations before your SCI, with other people like you, or did you decide in some other way?

10. Do you have family? Who do you include when the word "family" is used?
Or Who would you call "family"?
Considering the people you mentioned as family, how satisfied... (ask item)
When answering this question, what kinds of things did you think about?
Were you thinking of the health of a specific family member, about each family member, all of them together, or some other way?
Who was the family member you thought about?
Why did you think of this person in particular?

11. Do you have children? How many? (if not - skip question)
When answering this question, what kinds of things are you thinking about?
Did you think about one child in particular, all your children together, or in some other way?
Why did you think of this child in particular?

12. In general, what kinds of things do you think about when I say "happiness"?
Did you think about the happiness of one specific family member, each family member, or in some other way?
Who was the family member and why did you think of this person in particular?
When answering, did you compare your family's happiness to some time in the past, the happiness of other families, or did you not make any comparisons?
Did you think of your own happiness when answering these questions?

13. What did you think about when answering this question?
Did you have a relationship with this person before your SCI?
Has it changed since your SCI? How?

14. (answer even if not sexually active)
What kinds of things do you include when thinking about the words "sex life"?
Which of these things are you most satisfied with?
Which are you least satisfied with?
Have these things changed from before your SCI?

15. If you wanted (more) children, what do you think about your ability to have children?
When answering this question, what do you think about?

16. Why did you answer this way about your friends?
Did you think about one specific friend, more than one friend, or in some other way?
Who is the friend you thought about and why did you think of him/her in particular?

How many of your friends did you think about?
How did you decide which ones to include?
Has your relationship with your friends changed since your SCI?
What has changed?

17. What do you think I mean by "emotional support"?
Which family members did you think about when answering this question?

18. Which other people did you consider when answering this question?

19. What do you consider your "family responsibilities" to be?

20. When you think of "how useful you are", what kinds of things come to mind?
Did you compare your "usefulness" to some other time in the past, to other people, or to something else? (Specify)
Do you think the question about "how useful you are" and the question about "taking care of family responsibilities" are different or are really asking about the same thing? (Specify)

21. Could you tell me in your own words what this question is asking about?
What do you think of when I say "worries"?
Have your worries changed since your SCI? (Specify)

22. What kinds of things did you think about when answering this question about your neighborhood?

23. What do think this question is asking about the place where you live?
Why do you feel this way about the place where you live?
What things about the place where you live did you think about when answering this question?

24. Do you currently have a job? (if no - skip to 25.)
Did you think about specific things about your job when answering this question or did you think about your job in general?
What sorts of specific things did you think about?
Do you have more than one job?
When answering, did you consider one job, all jobs, or did you think of it in some other way? (Why one job in particular?)

25. What about not having a job is satisfying?
What about not having a job is dissatisfying?

26. What kinds of things did you think about when answering this question about your education?
In answering this question, did you compare yourself with other people or did you make some other comparison?

27. What kinds of things did you think of when answering this question about your financial needs?

28. What comes to mind when you think of the "things you do for fun"?
Do you have time to do things for fun?

29. What do you think I am asking in this question?
What does a "happy future" mean to you?
Have you ever thought about the future before now?
What sorts of things have you thought about?

30. What does the phrase "peace of mind" mean to you?
What kinds of things did you think about in answering this question?

31. Do you believe there is a God or a higher power?
When answering the question, what sorts of things did you think about?

32. What personal goals did you think about?
Before I asked this question, had you ever thought about your goals?

33. What kinds of things did you think about when I said "happiness"?
Did you compare your happiness now with another time? (When?)

34. What kinds of things did you think about?
Did you have trouble understanding the difference between this question about your life in general and the one just before, which asked about your happiness?
Do you think the two questions are different or are really asking the same thing? (Specify)

35. When you think of your "personal appearance", what kinds of things come to mind?
Did you compare yourself now to how you used to look, to other people, or did you not make any comparisons? (Specify)

36. What do you think I am asking in this question?
What specific things did you think about when answering this question?

**Post-Interview Questions**
Is there anything else that is important in your life that I did not ask you about?
What would they be?
How hard were these questions to understand? For instance, were the questions clearly worded?
Were there any questions that you felt embarrassed or uncomfortable about answering? Specify.
How hard were these questions for you emotionally?

## **Appendix E** Information Letter to Potential Participants – Phase 2

Dear

I am a physical therapist who has worked in the area of spinal cord injury rehabilitation since 1986. In my work as a therapist at the Aberhart and the Glenrose and as the wife of a paraplegic, I have become very interested in the quality of life for persons with spinal cord injury. I think this issue is very important since the goal of rehabilitation is to improve the quality of life for people with disabilities. It is for this reason that I have decided to research this area as a part of my Ph.D. studies. The *Canadian Paraplegic Association* has agreed to help me by sending this letter to you on my behalf.

I am writing to you to request your help with the research that I am doing. I am trying to find out if a questionnaire that measures Quality of Life really does what it is supposed to. You would be required to attend one appointment with myself at a place you choose and when it is convenient for you. This visit would last about 2 hours. I will be studying how the physical aspects of spinal cord injury and other factors such as self esteem relate to quality of life. To do this I will ask you to fill out some questionnaires and I will examine the strength of some of your muscles. All of the information will be kept confidential.

The information you can offer will be of great help to researchers and those working in rehabilitation. Although you may not personally benefit, you can help us understand aspects of life that are important to persons like yourself and hopefully improve the rehabilitation services we offer. If interested, we can send you a summary of the results at the end of the study.

Your participation would be greatly appreciated. Please fill out the information requested on the following page and return it in the postage paid envelope. If you prefer, you can contact me directly at 492 - 7499 (you may call collect). Once you have indicated your interest in participation, I will contact you to discuss the study further.

If you have any questions about this study please do not hesitate to call. Thank you for considering my request.

Sincerely,

Laura May M.Sc PT
Ph.D. Student
Faculty of Rehabilitation Medicine
3-50 Corbett Hall
University of Alberta
Edmonton T6G 2G4

Please fill out the following information and return in the postage paid envelope.

Name ______________________________

_____ Yes, I would be interested in participating in your research project.

You can contact me at: (day) ______________

(evening) ______________

_____ No, I will not be able to participate in your research project due to the following reason:

______________________________________________________

______________________________________________________

Thank you.

## **Appendix F** Consent Form – Phase 2

Measurement of Quality of Life of Spinal Cord Injured Persons: A Validation Study

Investigators: L. May, PhD candidate, Rehabilitation Medicine
Dr. S. Warren, Professor, Rehabilitation Medicine
Dr. R. Burnham, Associate Professor, Medicine
Dr. J. Golec, Assistant Professor, Sociology
Dr. L. Liu, Associate Professor, Occupational Therapy
Dr. T. Maguire, Professor, Educational Psychology

**Purpose:** The purpose of this project is to find out if an instrument that measures quality of life really does what it is supposed to. To do this, we need to find out if the results using this instrument are related to other measurements in the way we expect. During an interview with the researcher at a place you choose, you will be asked to answer some questionnaires. These will include information about quality of life, how you do everyday activities, your community activities, how you feel about yourself and how you view life situations. You will also have the strength of some of your muscles tested. The interview will take about two hours. The information about quality of life may also be used to find out what factors, measured at discharge from rehabilitation tell us about future quality of life.

**Consent:** I, ________________________, (please print) agree to participate in the above named project which has been completely described to me. I understand that my participation is voluntary and I may withdraw from the study at any time without any effects on my present or future care. I may refuse to answer any questions if I so choose. I realize that I may not necessarily benefit from the study. I understand that my muscles might be sore after the testing.

I understand that all information will be kept confidential. My name will not appear on any questionnaires, only an identifying code number. My name will not be associated with anything written about this project as only summary information will be presented.

All the questions I had about this project have been answered. I understand that I may call Laura May at 492 - 7499 or Dr. Sharon Warren at 492 - 7856, if I have any further questions.

I have read and understood the information stated above and I sign this consent form willingly. I will receive a copy of this consent form for my records.

| | |
|---|---|
| Participant's Signature | Date |
| Investigator's Signature | Date |

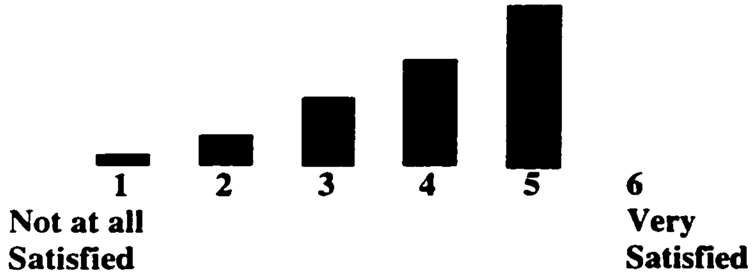
# **Appendix G** QLI Version Used in Phase 2

### Ferrans and Powers
## Quality of Life Index
## Spinal Cord Injured Version

Part 1: For each of the following, please choose the answer that best describes **how satisfied** you are with that area of your life. Please mark your answer by circling the number using the scale below, from 1, if you are not at all satisfied to 6, if you are very satisfied. There are no right or wrong answers.

Response Categories:
(Choose one of the lettered responses only if you are not choosing a numbered response)

| | |
|---|---|
| A | Question not relevant (does not apply) |
| B | Could not answer this question (didn't understand it) |
| C | Refuse to answer |



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**HOW SATISFIED ARE YOU WITH:**

| | | | | | | | | | |
|---|---|---|---|---|---|---|---|---|---|
| 1. Your health? | 1 | 2 | 3 | 4 | 5 | 6 | A | B | C |
| 2. The health care you are receiving? | 1 | 2 | 3 | 4 | 5 | 6 | A | B | C |
| 3. The amount of pain that you have? | 1 | 2 | 3 | 4 | 5 | 6 | A | B | C |
| 4. Your ability to clear your lungs? | 1 | 2 | 3 | 4 | 5 | 6 | A | B | C |
| 5. Your ability to take care of yourself without help? | 1 | 2 | 3 | 4 | 5 | 6 | A | B | C |
| 6. Your ability to go places outside your home? | 1 | 2 | 3 | 4 | 5 | 6 | A | B | C |
| 7. The amount of energy you have for everyday activities? | 1 | 2 | 3 | 4 | 5 | 6 | A | B | C |

## HOW SATISFIED ARE YOU WITH:

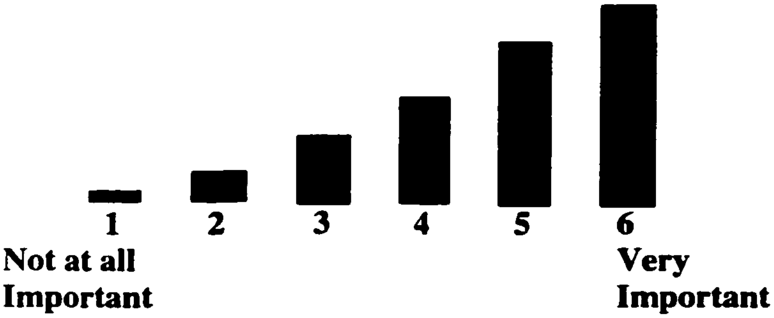
| | | |
|---|---|---|
| 8. The amount of control you have over your life? | 1 2 3 4 5 6 | A B C |
| 9. Your chances of living as long as you would like? | 1 2 3 4 5 6 | A B C |
| 10. Your family's health? | 1 2 3 4 5 6 | A B C |
| 11. Your children? | 1 2 3 4 5 6 | A B C |
| 12. Your ability to have children? | 1 2 3 4 5 6 | A B C |
| 13. Your family's happiness? | 1 2 3 4 5 6 | A B C |
| 14. Your spouse, lover or partner? (if you have one) | 1 2 3 4 5 6 | A B C |
| 15. Not having a spouse, lover or partner? (if you do not have one) | 1 2 3 4 5 6 | A B C |
| 16. Your sex life? | 1 2 3 4 5 6 | A B C |
| 17. Your friends? | 1 2 3 4 5 6 | A B C |
| 18. The emotional support you get from your family? | 1 2 3 4 5 6 | A B C |
| 19. The emotional support you get from people other than your family? | 1 2 3 4 5 6 | A B C |
| 20. Your ability to take care of family responsibilities? | 1 2 3 4 5 6 | A B C |
| 21. How useful you are to others? | 1 2 3 4 5 6 | A B C |
| 22. The amount of worries in your life? | 1 2 3 4 5 6 | A B C |
| 23. Your neighborhood? | 1 2 3 4 5 6 | A B C |
| 24. Your home, apartment, or place where you live? | 1 2 3 4 5 6 | A B C |

**HOW SATISFIED ARE YOU WITH:**

| | | | | | | | | | |
|---|---|---|---|---|---|---|---|---|---|
| 25. Your job (if employed)? | 1 | 2 | 3 | 4 | 5 | 6 | A | B | C |
| 26. Not having a job (if unemployed, retired, or disabled)? | 1 | 2 | 3 | 4 | 5 | 6 | A | B | C |
| 27. Your education? | 1 | 2 | 3 | 4 | 5 | 6 | A | B | C |
| 28. How well you can take care of your financial needs? | 1 | 2 | 3 | 4 | 5 | 6 | A | B | C |
| 29. The things you do for fun? | 1 | 2 | 3 | 4 | 5 | 6 | A | B | C |
| 30. Your chances for a happy future? | 1 | 2 | 3 | 4 | 5 | 6 | A | B | C |
| 31. Your peace of mind? | 1 | 2 | 3 | 4 | 5 | 6 | A | B | C |
| 32. Your faith, whatever that means to you? | 1 | 2 | 3 | 4 | 5 | 6 | A | B | C |
| 33. Your achievement of personal goals? | 1 | 2 | 3 | 4 | 5 | 6 | A | B | C |
| 34. Your happiness in general? | 1 | 2 | 3 | 4 | 5 | 6 | A | B | C |
| 35. Your life in general? | 1 | 2 | 3 | 4 | 5 | 6 | A | B | C |
| 36. Your personal appearance? | 1 | 2 | 3 | 4 | 5 | 6 | A | B | C |
| 37. Yourself in general? | 1 | 2 | 3 | 4 | 5 | 6 | A | B | C |

Part 2: For each of the following, please choose the answer that best describes **<u>how important</u>** that area of life is to you. Please mark your answer by <u>circling the number</u> using the scale below from 1, not at all important to 6, very important. There are no right or wrong answers.

<u>Response Categories:</u>
(Choose one of the lettered responses only if you are <u>not</u> choosing a numbered response)
A	Question not relevant (does not apply)
B	Could not answer this question (didn't understand it)
C	Refused to answer



## HOW <u>IMPORTANT</u> TO YOU IS / ARE:

| | | |
|---|---|---|
| 1. Your health? | 1 2 3 4 5 6 | A B C |
| 2. The health care you are receiving? | 1 2 3 4 5 6 | A B C |
| 3. Having no pain? | 1 2 3 4 5 6 | A B C |
| 4. Being able to clear your lungs? | 1 2 3 4 5 6 | A B C |
| 5. Taking care of yourself without help? | 1 2 3 4 5 6 | A B C |
| 6. Being able to go places outside your home? | 1 2 3 4 5 6 | A B C |
| 7. Having enough energy for everyday activities? | 1 2 3 4 5 6 | A B C |
| 8. Having control over your life? | 1 2 3 4 5 6 | A B C |
| 9. Living as long as you would like? | 1 2 3 4 5 6 | A B C |
| 10. Your family's health? | 1 2 3 4 5 6 | A B C |

**HOW IMPORTANT TO YOU IS / ARE:**

11. Your children? 1 2 3 4 5 6 A B C

12. Being able to have children? 1 2 3 4 5 6 A B C

13. Your family's happiness? 1 2 3 4 5 6 A B C

14. Your spouse, lover or partner? (if you have one) 1 2 3 4 5 6 A B C

15. Having a spouse, lover or partner? (if you do not have one) 1 2 3 4 5 6 A B C

16. Your sex life? 1 2 3 4 5 6 A B C

17. Your friends? 1 2 3 4 5 6 A B C

18. The emotional support you get from your family? 1 2 3 4 5 6 A B C

19. The emotional support you get from people other than your family? 1 2 3 4 5 6 A B C

20. Taking care of family responsibilities? 1 2 3 4 5 6 A B C

21. Being useful to others? 1 2 3 4 5 6 A B C

22. Having no worries? 1 2 3 4 5 6 A B C

23. Your neighborhood? 1 2 3 4 5 6 A B C

24. Your home, apartment, or place where you live? 1 2 3 4 5 6 A B C

25. Your job (if employed)? 1 2 3 4 5 6 A B C

26. Having a job (if unemployed, retired, or disabled)? 1 2 3 4 5 6 A B C

27. Your education? 1 2 3 4 5 6 A B C

28. Being able to take care of your financial needs? 1 2 3 4 5 6 A B C

**HOW IMPORTANT TO YOU IS / ARE:**

| | | |
|---|---|---|
| 29. Doing things for fun? | 1 2 3 4 5 6 | A B C |
| 30. Having a happy future? | 1 2 3 4 5 6 | A B C |
| 31. Peace of mind? | 1 2 3 4 5 6 | A B C |
| 32. Your faith, whatever that means to you? | 1 2 3 4 5 6 | A B C |
| 33. Achieving your personal goals? | 1 2 3 4 5 6 | A B C |
| 34. Your happiness in general? | 1 2 3 4 5 6 | A B C |
| 35. Being satisfied with life? | 1 2 3 4 5 6 | A B C |
| 36. Your personal appearance? | 1 2 3 4 5 6 | A B C |
| 37. You to yourself? | 1 2 3 4 5 6 | A B C |

## **Appendix H** Scoring Procedure for the Quality of Life Index

| **Steps** | **Calculations** |
|---|---|
| 1. Recode satisfaction scores | To center the scale on zero, subtract 3.5 from the satisfaction response for each item. (This will produce responses of -2.5, -1.5, -.5, +.5, +1.5, +2.5) |
| 2. Weight satisfaction responses with the paired importance responses | Multiply the recoded satisfaction response by the raw importance response for each pair of satisfaction and importance items. |
| 3. Obtain preliminary sum for the overall (total) score | Add together the weighted responses obtained in step 2 for all of the items. |
| 4. Obtain final overall (total) QLI score | To prevent bias due to missing data, divide each sum obtained in step 3 by the number of items answered by that individual. (At this point the possible range for scores is –15 to +15) Next, to eliminate negative numbers for the final score, add 15 to every score. This will produce the final overall (total) QLI score. (Possible range for the final scores = 0 to 30) |

The same steps are used to calculate the subscale scores as total scores. The only difference is that the calculations are performed using subsets of items, rather than on all of the items. The possible range for the subscale scores is the same as for the total score.

# Appendix I ASIA Standard Neurological Classification of Spinal Cord Injury

## ASIA Motor Score

| | Right | Left |
|---|---|---|
| Elbow Flexors | ____ | ____ |
| Wrist Extensors | ____ | ____ |
| Elbow Extensors | ____ | ____ |
| Finger Flexors (distal phalanx, 3rd finger) | ____ | ____ |
| Finger Abductors (little finger) | ____ | ____ |
| Hip Flexors | ____ | ____ |
| Knee Extensors | ____ | ____ |
| Ankle Dorsiflexors | ____ | ____ |
| Long Toe Extensors | ____ | ____ |
| Ankle Plantar Flexors | ____ | ____ |
| **Total** | ____ | ____ |

**Motor Score = Right + Left** ____

**Scoring**

**0** = total paralysis

**1** = palpable or visible contraction

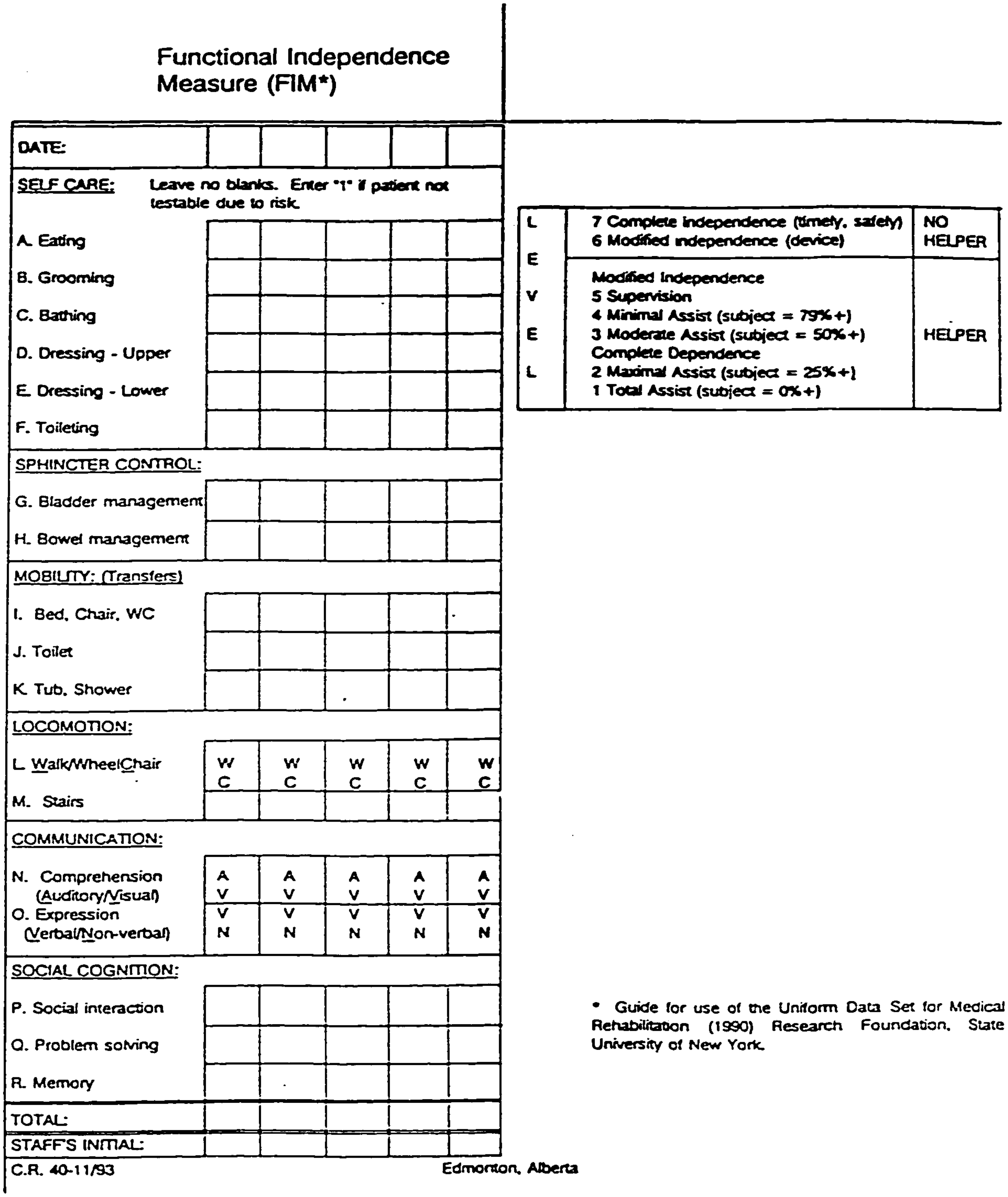
**2** = active movement, gravity eliminated

**3** = active movement, against gravity

**4** = active movement, with some resistance

**5** = active movement, with max resistance

# Appendix J Functional Independence Measure



## Functional Independence Measure (FIM*)

| | | | | | |
|---|---|---|---|---|---|
| DATE: | | | | | |
| SELF CARE: Leave no blanks. Enter "1" if patient not testable due to risk. | | | | | |
| A. Eating | | | | | |
| B. Grooming | | | | | |
| C. Bathing | | | | | |
| D. Dressing - Upper | | | | | |
| E. Dressing - Lower | | | | | |
| F. Toileting | | | | | |
| SPHINCTER CONTROL: | | | | | |
| G. Bladder management | | | | | |
| H. Bowel management | | | | | |
| MOBILITY: (Transfers) | | | | | |
| I. Bed, Chair, WC | | | | | |
| J. Toilet | | | | | |
| K. Tub, Shower | | | | | |
| LOCOMOTION: | | | | | |
| L. Walk/WheelChair | W<br>C | W<br>C | W<br>C | W<br>C | W<br>C |
| M. Stairs | | | | | |
| COMMUNICATION: | | | | | |
| N. Comprehension (Auditory/Visual) | A<br>V | A<br>V | A<br>V | A<br>V | A<br>V |
| O. Expression (Verbal/Non-verbal) | V<br>N | V<br>N | V<br>N | V<br>N | V<br>N |
| SOCIAL COGNITION: | | | | | |
| P. Social interaction | | | | | |
| Q. Problem solving | | | | | |
| R. Memory | | | | | |
| TOTAL: | | | | | |
| STAFF'S INITIAL: | | | | | |

| | | |
|---|---|---|
| L<br>E<br>V<br>E<br>L | 7 Complete independence (timely, safely)<br>6 Modified independence (device) | NO HELPER |
| | Modified Independence<br>5 Supervision<br>4 Minimal Assist (subject = 75%+)<br>3 Moderate Assist (subject = 50%+)<br>Complete Dependence<br>2 Maximal Assist (subject = 25%+)<br>1 Total Assist (subject = 0%+) | HELPER |

* Guide for use of the Uniform Data Set for Medical Rehabilitation (1990) Research Foundation, State University of New York.

C.R. 40-11/93

Edmonton, Alberta

# **Appendix K** Reintegration to Normal Living Index

**Instructions:**
Please mark an X within the bar to indicate how this statement applies to you **at this time**.

1. I move around my living quarters as I feel is necessary. (Wheelchairs or other equipment may be used.)

| | |
|---|---|
| Fully describes my situation | Does not describe my situation |

2. I move around my community as I feel is necessary. (Wheelchairs or other equipment may be used.)

| | |
|---|---|
| Fully describes my situation | Does not describe my situation |

3. I am able to take trips out of town as I feel are necessary. (Wheelchairs or other equipment may be used.)

| | |
|---|---|
| Fully describes my situation | Does not describe my situation |

4. I am comfortable with how my self-care needs (dressing, feeding, toileting, bathing) are met. (Adaptive equipment, supervision and/or assistance may be used.)

| | |
|---|---|
| Fully describes my situation | Does not describe my situation |

5. I spend most of my days occupied in a work activity that is necessary or important to me. (Work activity could be paid employment, housework, volunteer work, school, etc.

| | |
|---|---|
| Fully describes my situation | Does not describe my situation |

6. I am able to participate in recreational activities (hobbies, crafts, sports, reading, television, games, computers, etc.) as I want to.

| | |
|---|---|
| Fully describes my situation | Does not describe my situation |

7. I participate in social activities with family, friends, and/or business acquaintances as is necessary or desirable to me.

| | |
|---|---|
| Fully describes my situation | Does not describe my situation |

8. I assume a role in my family which meets my needs and those of other family members.
(Family means people with whom you live and/or relatives with whom you don't live but see on a regular basis. Adaptive equipment, supervision and/or assistance may be used.)

| | |
|---|---|
| Fully describes my situation | Does not describe my situation |

9. In general, I am comfortable with my personal relationships.

| | |
|---|---|
| Fully describes my situation | Does not describe my situation |

10. In general, I am comfortable with myself when I am in the company of others.

| | |
|---|---|
| Fully describes my situation | Does not describe my situation |

11. I feel that I can deal with life events as they happen.

| | |
|---|---|
| Fully describes my situation | Does not describe my situation |

## **Appendix L** Rosenberg's Self Esteem Scale

**Instructions:**
Circle one answer for each statement that describes how you feel about that statement.

On the whole, I am satisfied with myself.
1) Strongly Disagree
2) Disagree
3) Agree
4) Strongly Agree

At times I think I am no good at all.
1) Strongly Agree
2) Agree
3) Disagree
4) Strongly Disagree

I feel that I have a number of good qualities.
1) Strongly Disagree
2) Disagree
3) Agree
4) Strongly Agree

I am able to do things as well as most other people.
1) Strongly Disagree
2) Disagree
3) Agree
4) Strongly Agree

I feel that I do not have much to be proud of.
1) Strongly Agree
2) Agree
3) Disagree
4) Strongly Disagree

I certainly feel useless at times.
1) Strongly Agree
2) Agree
3) Disagree
4) Strongly Disagree

I feel that I am a person of worth, at least on an equal plane with others.
1) Strongly Disagree
2) Disagree
3) Agree
4) Strongly Agree

I wish I could have more respect for myself.
1) Strongly Agree
2) Agree
3) Disagree
4) Strongly Disagree

All in all, I am inclined to feel that I am a failure.
1) Strongly Agree
2) Agree
3) Disagree
4) Strongly Disagree

I take a positive attitude toward myself.
1) Strongly Disagree
2) Disagree
3) Agree
4) Strongly Agree

## **Appendix M** Rotter's Internal-External Locus of Control Scale

**Instructions:**
This is a questionnaire to find out the way in which certain important events in our society affect different people. Each item consists of a pair of alternatives lettered **a** or **b**. Please select the one statement of each pair (***and only one***) which ***you*** more strongly ***believe*** to be the case as far as you are concerned. Be sure to select the one you actually believe to be more true rather than the one you think you should choose or the one you would like to be true. This is a measure of personal belief, ***there are no right or wrong answers***.

1. a. Children get into trouble because their parents punish them too much.
   b. The trouble with most children nowadays is that their parents are too easy with them.

2. a. Many of the unhappy things in people's lives are partly due to bad luck.
   b. People's misfortunes result from the mistakes they make.

3. a. One of the major reasons why we have wars is because people don't take enough interest in politics.
   b. There will always be wars, no matter how hard people try to prevent them.

4. a. In the long run people get the respect they deserve in this world.
   b. Unfortunately, an individual's worth often passes unrecognized no matter how hard he tries.

5. a. The idea that teachers are unfair to students is nonsense.
   b. Most students don't realize the extent to which their grades are influenced by accidental happenings.

6. a. Without the right breaks one cannot be an effective leader.
   b. Capable people who fail to become leaders have not taken advantage of their opportunities.

7. a. No matter how hard you try some people just don't like you.
   b. People who can't get others to like them don't understand how to get along with others.

8. a. Heredity plays the major role in determining one's personality.
   b. It is one's experience in life which determine what they are like.

9. a. I have often found that what is going to happen will happen.
   b. Trusting to fate has never turned out as well for me as making a decision to take a definite course of action.

10. a. In the case of the well prepared student there is rarely if ever such a thing as an unfair test.
    b. Many times exam questions tend to be so unrelated to course work that studying is really useless.

11. a. Becoming a success is a matter of hard work, luck has little or nothing to so with it.
    b. Getting a good job depends mainly on being in the right place at the right time.

12. a. The average citizen can have an influence in government decisions.
    b. This world is run by the few people in power, and there is not much the little guy can do about it.

13. a. When I make plans, I am almost certain that I can make them work.
    b. It is not always wise to plan too far ahead because many things turn out to be a matter of good or bad fortune anyhow.

14. a. There are certain people who are just no good.
    b. There is some good in everybody.

15. a. In my case getting what I want has little or nothing to do with luck.
    b. Many times we might just as well decide what to do by flipping a coin.

16. a. Who gets to be the boss often depends on who was lucky enough to be in the right place first.
    b. Getting people to do the right thing depends upon ability, luck has little or nothing to do with it.

17. a. As far as world affairs are concerned, most of us are victims of forces we can neither understand, nor control.
    b. By taking an active part in political and social affairs the people can control world events.

18. a. Most people don't realize the extent to which their lives are controlled by accidental happenings.
    b. There really is no such thing as "luck."

19. a. One should always be willing to admit mistakes.
    b. It is usually best to cover up one's mistakes.

20. a. It is hard to know whether or not a person really likes you.
    b. How many friends you have depends upon how nice a person you are.

21. a. In the long run the bad things that happen to us are balanced by the good ones.
    b. Most misfortunes are the result of the lack of ability, ignorance, laziness, or all three.

22. a. With enough effort we can wipe out political corruption.
    b. It is difficult for people to have much control over things politicians do in office.

23. a. Sometimes I can't understand how teachers arrive at the grades they give.
    b. There is a direct connection between how hard I study and the grades I get.

24. a. A good leader expects people to decide for themselves what they should do.
    b. A good leader makes it clear to everybody what their jobs are.

25. a. Many times I feel that I have little influence over the things that happen to me.
    b. It is impossible for me to believe that chance or luck plays an important role in my life.

26. a. People are lonely because they don't try to be friendly.
    b. There's not much use in trying too hard to please people, if they like you, they like you.

27. a. There is too much emphasis on athletics in high school.
    b. Team sports are an excellent way to build character.

28. a. What happens to me is my own doing.
    b. Sometimes I feel that I don't have enough control over the direction my life is taking.

29. a. Most of the time I can't understand why politicians behave the way they do.
    b. In the long run the people are responsible for bad government on a national as well as on a local level.

# Appendix N Contract - Alberta Spine Trauma Study Group
## CONTRACT

MEMORANDUM OF AGREEMENT between

Laura Anne May, hereinafter referred to as the Recipient.

and,

The University of Alberta Spine Trauma Study Group, hereinafter referred to as the Custodian,

on the dissemination of the data file entitled SPINE2, which is described in the users guide **"FACTORS AND OUTCOMES OF TRAUMATIC SPINE INJURIES TREATED AT UAH 1983-1995: A PROSPECTIVELY GATHERED LONGITUDINAL DATA BASE"**

PRODUCED BY: David C. Reid, Lyle A. Davis, Linda A. Saboe, Sharon A. Warren

---

The above named data file, and accompanying documentation, is released to the Recipient under the following terms and conditions:

1. The Recipient agrees to, under no circumstances, directly contact any subjects entered into the data base without prior consent from the subject(s). This consent will be obtained by the Custodian who will forward a letter; informed consent; and return self-addressed stamped envelope provided by the Recipient to appropriate subjects. The Custodian will provide a covering letter. All mailing and postage costs will be paid by the Recipient.

2. The Recipient shall act at all times so as to preserve the individual confidentiality of data base subjects and their replies. The Recipient agrees to under no circumstances make hospital identification numbers or subject names accessible to any person(s) other than the principal investigator, or his/her designate, and in so doing assumes full and total responsibility for maintaining confidentiality within his/her subset.

3. The Custodian makes no representations or warranties, expressed or implied, as to merchantability, fitness for any particular purpose, or otherwise with respect to the machine readable data file or the related documentation provided. The Custodian shall not be liable to the Recipient for any design, performance or other fault or inadequacy of the machine readable data file or related documentation, or for damages of any kind arising out of, or in any way related to, or connected with such fault or inadequacy.

4. The Recipient shall at all times indemnify and save harmless the Custodian from and against all claims, losses, damages, costs, expenses, actions and other proceedings made, sustained, brought, prosecuted, threatened to be brought or prosecuted, in any manner based upon, caused by, or in any way attributable to the use of the machine readable data file and related documentation.

5. The Custodian and their agents and funding agencies bear no responsibility for uses of this collection or for interpretations or inferences based upon such uses. Should use of the data result in publication, the Recipient will ensure that the publication includes a disclaimer to the effect that neither the

Custodian nor their agents and funding agencies bear any responsibility for the analyses or interpretations contained therein. The Recipient shall use the following form of disclaimer:

> This analysis is based on University of Alberta Spine Trauma Study Group, Factors and outcomes of traumatic spine injuries treated at UAH 1983-1995: A prospectively gathered longitudinal data base, which contains anonymous data collected from 1983 to 1995. All computations on these microdata were prepared by Laura May and the responsibility for the use and interpretation of these data is entirely that of the Recipient, Laor a May.

6. Should use of the data file result in publication, the Recipient will acknowledge this source by means of bibliographic citations. To ensure that such source attributions are captured for social science bibliographic utilities; to provide funding agencies with essential information about use of archival resources and to facilitate exchange of information about the University of Alberta Spine Trauma Study Group's participants' research activities, citations must appear in footnotes or in the reference section of publications or thesis abstracts. The bibliographic citation for this data collection is:

> Reid DC, Davis LA, Saboe LA, Warren SA. Factors and outcomes of traumatic spine injuries treated at UAH 1983-1995: A prospectively gathered longitudinal data base, 2nd Edition. Edmonton, Alberta, 1995.

7. Should the data file be used for publication purposes, the Recipient will ensure that one (1) copy of each completed manuscript or thesis abstract is forwarded to the Principal Investigator, University of Alberta Spine Trauma Study Group:

> David C. Reid, MD
> Department of Surgery
> 2D2.29 Walter C. Mackenzie Centre
> University of Alberta
> Edmonton, AB T6G 2B7

8. The Recipient of a subfile agrees to pay all computer and programming costs of subfile development. Programming will be done by the Custodian's Programming Consultant,________________________, and his services will be billed through the Recipient's University Account.

9. The machine readable data file and related documentation shall at all times be and remain the sole and exclusive property of the Custodian. It is mutually agreed that this Agreement involves a licence for the use of the machine readable data file and related documentation and that nothing contained herein shall be deemed to convey title or ownership interest in the machine readable data file or the documentation related to it.

10. No duplicates or copies of all or any part of the machine readable data file shall be made by the Recipient except for backup purposes, nor shall they be made accessible to others without written permission of the Custodian.

11. The Recipient of a subfile agrees to provide the Custodian with a machine readable data file and a dictionary of variables added. This process will be arranged to the satisfaction of the Programming Consultant of the University of Alberta Spine Trauma Study Group. The medium agreed to by the parties is ________________________.

12. The Recipient hereby nominates ______________________________ as the contact person to whom all further communication shall be addressed by the Custodian on any matter concerning this Agreement. This contact person may only be changed upon written notice delivered to the Custodian.

13. The Custodian nominates ______________________________ as the designated custodian of the microdata file with responsibility for ensuring its proper use pursuant to the terms of this Agreement.

14. This Agreement comes into force when signed by both parties and shall continue in force until terminated.

15. The Custodian may, by providing written notice to the Recipient, at the address identified herein, terminate this Agreement at any time.

Address: 3-50 Corbett Hall, Faculty of Rehabilitation Medicine,
University of Alberta, Edmonton, AB T6G 2G4

16. Where this Agreement is terminated before the Recipient has been sent the machine readable data file, the Custodian shall not refund to the Recipient any monies paid or deposited for subfile development.

17. Where this Agreement is terminated after the Recipient has been sent the machine readable data subfile the Recipient shall return that subfile and related documentation to the Custodian immediately upon receipt of the notice of termination.

18. This Agreement can only come into effect when the Recipient provides appropriate Ethics Approval, and will automatically expire when said ethics approval expires (Ethics Approval is to be attached to this document).

19. No amendment to this Agreement shall be valid unless it is reduced to writing and signed by the Recipient, the Custodian, and duly witnessed.

20. This Agreement constitutes the entire agreement between the parties with respect to the subject matter hereof and supersedes all previous negotiations, communications and other agreements unless they are incorporated by reference in this Agreement.

21. The Custodian hereby grants only non-exclusive, non-assignable and non-transferable licences to use the machine readable data file and related documentation provided.

For the CUSTODIAN:

Name:
Title: Professor

Susan Sanger
Witness

For the RECIPIENT:

Name: Laura A. May
Title: Ph. D. (candidate)

Lisa [illegible]
Witness

Dated this 20 day of May, 1998, Edmonton, Alberta, Canada.

## **Appendix O** Information Letter to Potential Participants – Phase 3

Dear

I am a physical therapist who has worked in the area of spinal cord injury rehabilitation since 1986. In my work as a therapist at the Aberhart and the Glenrose and as the wife of a paraplegic, I have become very interested in the quality of life for persons with spinal cord injury. I think this issue is very important since the goal of rehabilitation is to improve the quality of life for people with disabilities. It is for this reason that I have decided to study this area as a part of my Ph.D. research. The Canadian Paraplegic Association has agreed to help me by sending this letter to you on my behalf.

I am writing to you to request your help with the research that I am doing. I am trying to find out what factors, measured at discharge tell us about future quality of life. To do this I will ask you to fill out some questionnaires. One questionnaire asks you information about yourself and the other questionnaire asks about your quality of life. It should take about 20 minutes to answer the questionnaires. All of the information will be kept confidential. Please do not write your name on any of the sheets.

The information you can offer will be of great help to researchers and those working in rehabilitation. Although you may not personally benefit, you can help us understand aspects of life that are important to persons like yourself and hopefully improve the rehabilitation services we offer. If interested, we can send you a summary of the results at the end of the study.

Your participation would be greatly appreciated. If interested in participating, please sign the consent form, fill out the information requested and return all papers in the postage paid envelope. If you have any questions about this project, you can contact me directly at 492-9110 or 471-2262 ext.2345 (you may call collect). Thank you for considering my request.

Sincerely,

Laura May M.Sc PT
Ph.D. Student
Faculty of Rehabilitation Medicine
3-50 Corbett Hall
University of Alberta
Edmonton T6G 2G4

## **Appendix P** Consent Form: Phase 3

Measurement of Quality of Life of Spinal Cord Injured Persons

Investigators: L. May, PhD candidate, Rehabilitation Medicine
Dr. S. Warren, Professor, Rehabilitation Medicine
Dr. R. Burnham, Associate Professor, Medicine
Dr. J. Golec, Assistant Professor, Sociology
Dr. L. Liu, Associate Professor, Occupational Therapy
Dr. T. Maguire, Professor, Educational Psychology

**Purpose:** The purpose of this project is to find out what factors, measured at discharge from rehabilitation tell us about future quality of life. Because you have had a spinal cord injury that has occurred within the past 20 years, you are being asked to participate. You are asked to answer questions about your quality of life. The questionnaire has two parts: how satisfied you are with certain areas of your life and how important these areas are to you. Also there is a sheet to fill out that asks you for information about yourself. It will take about 20 minutes to fill out the questionnaires.

**Consent:** I, __________________________, (please print) agree to participate in the above named project which has been completely described to me. I understand that my participation is voluntary and I may withdraw from the study at any time without any effects on my present or future care. I may refuse to answer any questions if I so choose. I realize that I may not necessarily benefit from the study.

I understand that all information will be kept confidential. My name will not appear on any questionnaires, only an identifying code number. My name will not be associated with anything written about this project as only summary information will be presented.

All the questions I had about this project have been answered. I understand that I may call Laura May at 492 - 7499 or Dr. Sharon Warren at 492 - 7856, if I have any further questions.

I have read and understood the information stated above and I sign this consent form willingly. I will receive a copy of this consent form for my records.

| | |
|---|---|
| Participant's Signature | Date |
| Witness' Signature | Date |
| Investigator's Signature | Date |

# Appendix Q Item Groupings by Phase 1 Participants

**Participant #1**

1. 1, 2, 4, 7, 9, 10, 16, 17, 18, 20, 35, 36.
2. 3, 21, 24, 25, 27, 33.
3. 5, 6, 8, 14, 19, 28.
4. 11, 22, 23, 26, 29, 30, 32.
5. 12, 13, 15, 35.
6. 31

**Participant #2**

1. 9, 11, 15, 21, 22.
2. 3, 5, 6, 8, 19, 23, 27, 30.
3. 24,25.
4. 20, 26, 29, 32.
5. 1, 2, 4, 7, 35.
6. 10, 12, 13, 14, 16, 17, 18, 28, 31, 33, 34, 36.

**Participant #3**

1. 18, 22, 23.
2. 13, 14.
3. 1, 2, 3, 4, 7, 9, 21.
4. 33, 34, 35, 36.
5. 5, 6, 8, 20, 27.
6. 24, 25, 26, 32.
7. 10, 11, 12, 15, 16, 17, 19, 29, 30, 31.
8. 28.

**Participant #4**

1. 1, 2, 3, 4, 10.
2. 9, 35, 36.
3. 11, 16, 17, 18.
4. 13, 14, 15.
5. 20
6. 21
7. 6, 22, 23.
8. 12, 28, 29, 33.
9. 5, 7, 8, 19, 32, 34.
10. 24, 25, 26, 27.
11. 30, 31.

**Participant #5**

1. 1, 2, 3, 4, 9.
2. 5, 6, 7, 8, 30.
3. 10, 11, 12, 17, 18.
4. 13, 14, 15, 21, 29.
5. 16, 19, 20, 28.
6. 22, 23.
7. 24, 25, 26, 31, 32.
8. 27, 33, 34, 35, 36.

**Participant #6**

1. 31.
2. 22, 23
3. 6, 16, 28.
4. 18, 20, 21, 29, 30, 32, 33, 34, 35, 36.
5. 13, 14, 15.
6. 9, 10, 11, 12, 17, 19.
7. 1, 2, 3, 4, 5, 7, 8.
8. 24, 25, 26, 27.

**Participant #7**

1. 1, 2, 3, 4, 5.
2. 6, 7, 8, 9.
3. 10, 11, 12, 13, 14, 15, 16, 17, 18, 19.
4. 20, 21.
5. 22, 23.
6. 24, 25, 26, 27.
7. 28, 29, 30.
8. 31, 32, 33, 34, 35, 36.

**Participant #8**

1. 1, 2, 3, 4, 5, 7, 9, 10, 11, 15, 30, 35.
2. 12, 13, 16, 33.
3. 6, 8, 28.
4. 17, 18.
5. 14, 19.
6. 22, 23.
7. 24, 25, 26, 27.
8. 20, 21, 29, 32, 34, 36.
9. 31.

**Participant #9**

1. 1, 2, 3, 4, 9.
2. 5, 8, 19, 20, 28, 30, 33, 35.
3. 10, 12, 17.
4. 11, 13, 14, 15.
5. 16, 18.
6. 6, 7, 21, 29.
7. 22, 23.
8. 24, 25, 26, 27, 32, 34, 36.
9. 31

**Participant #10**

1. 1, 2, 3, 4, 7, 18, 20.
2. 6, 9, 11, 12, 21, 22, 23, 24, 25, 26, 33, 34.
3. 3, 5, 10, 14, 16, 17, 19, 27, 29, 31.
4. 8, 15, 28, 30, 32, 35, 36.

**Participant #11**

1. 1, 2, 3, 4, 9.
2. 10, 11, 12, 17, 19.
3. 16, 18.
4. 22, 23.
5. 13, 14, 15, 20.
6. 8, 28, 36.
7. 7, 21, 24, 25, 26, 27, 30, 34.
8. 5, 6, 29, 31, 32, 33, 35.

## **Appendix R** Item Numbers for the Domains of the Quality of Life Index

### Health and Functioning

1. health
2. health care
3. pain
4. clear lungs
5. independence
6. ability of go places
7. energy
8. control over life
9. long life
14. sex life
15. ability to have children
19. family responsibilities
20. usefulness to others
21. worries
28. do things for fun
29. happy future

### Social and Economic

16. friends
17. emotional support from family
18. emotional support from others
22. neighborhood
23. home
24. job
25. no job
26. education
27. financial needs

### Psychological and Spiritual

30. peace of mind
31. faith
32. goals
33. happiness
34. life satisfaction
35. personal appearance
36. self

### Family

10. family health
11. children
12. family happiness
13. spouse

## Appendix S Participant's Item Ranking within each Domain and Corresponding Scores

**Participant #1**

| H& F Item | Scores S, I, W * | S&E Item | Scores | P&S Item | Scores | F Item | Scores |
|---|---|---|---|---|---|---|---|
| 1 | 3 , 6 , -3 | 17 | 2 , 6 , -9 | 30 | 2 , 6 , -9 | 11 | 6 , 6 , 15 |
| 2 | 5 , 6 , 9 | 16 | 5 , 6 , 9 | 32 | 1 , 6 , -15 | 10 | 5 , 6 , 9 |
| 8 | 2 , 6 , -9 | 26 | 4 , 6 , 3 | 33 | 4 , 6 , 3 | 12 | 2 , 6 , -9 |
| 3 | 3 , 6 , -3 | 23 | 2 , 5 , -7.5 | 35 | 2 , 6 , -9 | 13 | n/a |
| 5 | 1 , 6 , -15 | 22 | 3 , 5 , -2.5 | 36 | 3 , 6 , -3 | | |
| 4 | 5 , 6 , 9 | 27 | 5 , 6 , 9 | 34 | 2 , 6 , -9 | | |
| 20 | 1 , 6 , -15 | 18 | 5 , 6 , 9 | 31 | 5 , 6 , 9 | | |
| 21 | 1 , 6 , -15 | 25 | 1 , 6 , -15 | | | | |
| 7 | 4 , 6 , 3 | 24 | n/a | | | | |
| 6 | 4 , 6 , 3 | | | | | | |
| 14 | 1 , 6 , -15 | | | | | | |
| 29 | 6 , 6 , 15 | | | | | | |
| 15 | 5 , 4 , 6 | | | | | | |
| 28 | 2 , 6 , -9 | | | | | | |
| 19 | 2 , 6 , -9 | | | | | | |
| 9 | 5 , 4 , 6 | | | | | | |

* S - Satisfaction score, I - Importance score, W - Weighted score; Range of Satisfaction and Importance scores = 1 to 6; Range of Weighted scores = −15 to +15. Abbreviations: H&F – Health and Functioning; S&E – Social and Economic; P&S – Psychological and Spiritual; F – Family; n/a – Not Applicable

**Participant #2**

| H& F Item | Score | S&E Item | Score | P&S Item | Score | F Item | Score |
|---|---|---|---|---|---|---|---|
| 1 | 5 , 6 , 9 | 17 | 6 , 6 , 15 | 36 | 5 , 6 , 9 | 10 | 6 , 6 , 15 |
| 8 | 5 , 6 , 9 | 16 | 6 , 6 , 15 | 33 | 6 , 6 , 15 | 12 | n/a |
| 5 | 2 , 6 , -9 | 18 | 5 , 6 , 9 | 34 | 5 , 6 , 9 | 13 | 1 , 6 , -10 |
| 2 | 5 , 6 , 9 | 23 | 6 , 6 , 15 | 35 | 5 , 6 , 9 | 11 | n/a |
| 4 | 4 , 6 , 3 | 27 | 6 , 6 , 15 | 32 | 4 , 6 , 3 | | |
| 3 | 5 , 6 , 9 | 26 | 4 , 5 , 2.5 | 31 | 4 , 6 , 3 | | |
| 7 | 5 , 6 , 9 | 25 | 4 , 4 , 2 | 30 | 6 , 6 ,15 | | |
| 6 | 6 , 6 , 15 | 22 | 2 , 4 , -6 | | | | |
| 19 | n/a | 24 | n/a | | | | |
| 20 | 3 , 5 , -2.5 | | | | | | |
| 21 | 4 , 5 , 2.5 | | | | | | |
| 29 | 4 , 6 , 3 | | | | | | |
| 14 | 1 , 6 , -15 | | | | | | |
| 28 | 5 , 6 , 9 | | | | | | |
| 9 | 6 , 6 , 15 | | | | | | |
| 15 | 4 , 1 , .5 | | | | | | |

**Participant #3**

| H& F Item | Score | S&E Item | Score | P&S Item | Score | F Item | Score |
|---|---|---|---|---|---|---|---|
| 1 | 4 , 5 , 3 | 17 | 6 , 6 , 15 | 31 | 5 , 6 , 9 | 10 | 5 , 6 , 9 |
| 28 | 6 , 4 , 10 | 16 | 6 , 5 , 12.5 | 30 | 4 , 6 , 3 | 12 | 6 , 6 , 15 |
| 8 | 5 , 6 , 9 | 24 | n/a | 33 | 5 , 5 , 7.5 | 11 | n/a |
| 6 | 4 , 6 , 15 | 27 | 5 , 6 , 9 | 34 | 5 , 6 , 9 | 13 | n/a |
| 19 | 4 , 6 , 3 | 26 | 3 , 5 , -2.5 | 35 | 4 , 5 , 2.5 | | |
| 5 | 3 , 6 , -3 | 22 | 5 , 3 , 4.5 | 36 | 5 , 5 , 7.5 | | |
| 20 | 2 , 6 , -9 | 23 | 5 , 3 , 4.5 | 32 | 3 , 4 , -2 | | |
| 2 | 6 , 5 , 12.5 | 18 | 5 , 4 , 6 | | | | |
| 21 | 6 , 4 , 10 | 25 | 1 , 6 , -15 | | | | |
| 7 | 5 , 5 , 7.5 | | | | | | |
| 4 | 4 , 6 , 3 | | | | | | |
| 3 | 5 , 6 , 9 | | | | | | |
| 15 | 4 , 3 , 1.5 | | | | | | |
| 29 | 6 , 5 , 12.5 | | | | | | |
| 9 | 5 , 3 , 4.5 | | | | | | |
| 14 | 6 , 1 , 2.5 | | | | | | |

**Participant #4**

| H& F Item | Score | S&E Item | Score | P&S Item | Score | F Item | Score |
|---|---|---|---|---|---|---|---|
| 5 | 6 , 6 , 15 | 16 | 5 , 6 , 9 | 31 | 6 , 6 , 15 | 12 | 5 , 6 , 9 |
| 19 | 4 , 6 , 3 | 18 | 5 , 6 , 9 | 30 | 5 , 6 , 9 | 10 | 6 , 6 , 15 |
| 6 | 6 , 6 , 15 | 23 | 5 , 6 , 9 | 34 | 5 , 6 , 9 | 11 | 6 , 6 , 15 |
| 28 | 3 , 6 , -3 | 22 | 5 , 6 , 9 | 33 | 6 , 6 , 15 | 13 | 4 , 6 , 3 |
| 7 | 4 , 6 , 3 | 27 | 6 , 6 , 15 | 32 | 5 , 6 , 9 | | |
| 20 | 5 , 6 , 9 | 26 | 6 , 5 , 12.5 | 35 | 4 , 5 , 2.5 | | |
| 29 | 6 , 6 , 15 | 17 | 5 , 6 , 9 | 36 | 5 , 4 , 6 | | |
| 1 | 5 , 6 , 9 | 25 | 2 , 5 , -7.5 | | | | |
| 8 | 4 , 6 , 3 | 24 | n/a | | | | |
| 9 | 5 , 6 , 9 | | | | | | |
| 2 | 3 , 6 , -3 | | | | | | |
| 14 | 1 , 6 , -15 | | | | | | |
| 21 | 4 , 5 , 2.5 | | | | | | |
| 3 | 3 , 6 , -3 | | | | | | |
| 4 | 6 , 6 , 15 | | | | | | |
| 15 | 1 , 1 , -2.5 | | | | | | |

**Participant #5**

| H& F Item | Score | S&E Item | Score | P&S Item | Score | F Item | Score |
|---|---|---|---|---|---|---|---|
| 1 | 5 , 6 , 9 | 23 | 3 , 4 , -2 | 30 | 5 , 5 , 7.5 | 13 | 5 , 5 , 7.5 |
| 8 | 4 , 6 , 3 | 27 | 5 , 5 , 7.5 | 33 | 4 , 5 , 2.5 | 10 | 5 , 5 , 7.5 |
| 2 | 5 , 5 , 7.5 | 16 | 5 , 5 , 7.5 | 34 | 4 , 5 , 2.5 | 12 | 5 , 5 , 7.5 |
| 5 | 4 , 5 , 2.5 | 17 | 3 , 3 , -1.5 | 36 | 4 , 5 , 2.5 | 11 | n/a |
| 7 | 4 , 5 , 2.5 | 18 | 4 , 4 , 2 | 35 | 3 , 4 , -2 | | |
| 6 | 3 , 5 , -2.5 | 22 | 5 , 4 , 6 | 32 | 3 , 4 , -2 | | |
| 21 | 4 , 4 , 2 | 26 | 4 , 3 , 1.5 | 31 | 2 , 3 , -4.5 | | |
| 14 | 2 , 4 , -6 | 25 | 4 , 3 , 1.5 | | | | |
| 28 | 5 , 5 , 7.5 | 24 | n/a | | | | |
| 29 | 5 , 5 , 7.5 | | | | | | |
| 19 | 5 , 4 , 6 | | | | | | |
| 20 | 4 , 4 , 2 | | | | | | |
| 15 | 1 , 3 , -7.5 | | | | | | |
| 9 | 5 , 5 , 7.5 | | | | | | |
| 4 | 4 , 5 , 2.5 | | | | | | |
| 3 | 5 , 5 , 7.5 | | | | | | |

**Participant #6**

| H& F Item | Score | S&E Item | Score | P&S Item | Score | F Item | Score |
|---|---|---|---|---|---|---|---|
| 1 | 4 , 6 , 3 | 25 | 1 , 6 , -15 | 34 | 3 , 5 , -2.5 | 13 | n/a |
| 8 | 4 , 6 , 3 | 27 | 4 , 6 , 3 | 32 | 4 , 5 , 2.5 | 12 | 5 , 5 , 7.5 |
| 20 | 2 , 5 , -7.5 | 26 | 5 , 5 , 7.5 | 35 | 4 , 6 , 3 | 10 | 4 , 5 , 2.5 |
| 14 | 1 , 6 , -15 | 16 | 5 , 5 , 7.5 | 30 | 2 , 5 , -7.5 | 11 | n/a |
| 5 | 4 , 6 , 3 | 23 | 5 , 6 , 9 | 33 | 3 , 5 , -2.5 | | |
| 29 | 4 , 5 , 2.5 | 17 | 6 , 4 , 10 | 36 | 4 , 5 , 2.5 | | |
| 28 | 4 , 5 , 2.5 | 18 | 4 , 4 , 2 | 31 | 1 , 1 , -2.5 | | |
| 21 | 1 , 3 , -7.5 | 22 | 3 , 3 , -1.5 | | | | |
| 19 | 3 , 5 , -2.5 | 24 | n/a | | | | |
| 15 | 2 , 4 , -6 | | | | | | |
| 7 | 2 , 6 , -9 | | | | | | |
| 6 | 5 , 6 , 9 | | | | | | |
| 2 | 3 , 5 , -2.5 | | | | | | |
| 4 | 4 , 6 , 3 | | | | | | |
| 3 | 5 , 4 , 6 | | | | | | |
| 9 | 3 , 4 , -2 | | | | | | |

**Participant #7**

| H& F Item | Score | S&E Item | Score | P&S Item | Score | F Item | Score |
|---|---|---|---|---|---|---|---|
| 1 | 4 , 6 , 3 | 24 | 4 , 6 , 3 | 32 | 5 , 5 , 7.5 | 10 | 5 , 6 , 9 |
| 2 | 5 , 5 , 7.5 | 26 | 5 , 5 , 7.5 | 33 | 5 , 6 , 9 | 12 | 4 , 5 , 3 |
| 6 | 4 , 5 , 2.5 | 17 | 5 , 5 , 7.5 | 35 | 5 , 5 , 7.5 | 13 | 5 , 5 , 7.5 |
| 7 | 5 , 6 , 9 | 16 | 5 , 6 , 9 | 34 | 5 , 6 , 9 | 11 | n/a |
| 14 | 4 , 5 , 2.5 | 27 | 5 , 5 , 7.5 | 36 | 5 , 5 , 7.5 | | |
| 19 | 4 , 5 , 2.5 | 18 | 5 , 4 , 6 | 31 | 4 , 5 , 2.5 | | |
| 4 | 4 , 6 , 3 | 23 | 5 , 5 , 7.5 | 30 | 5 , 5 , 7.5 | | |
| 28 | 5 , 5 , 7.5 | 22 | 5 , 5 , 7.5 | | | | |
| 29 | 5 , 5 , 7.5 | 25 | n/a | | | | |
| 8 | 5 , 6 , 9 | | | | | | |
| 21 | 4 , 5 , 2.5 | | | | | | |
| 5 | 4 , 6 , 3 | | | | | | |
| 20 | 4 , 4 , 2 | | | | | | |
| 15 | 1 , 6 , -15 | | | | | | |
| 3 | 5 , 6 , 9 | | | | | | |
| 9 | 5 , 5 , 7.5 | | | | | | |

**Participant #8**

| H& F Item | Score | S&E Item | Score | P&S Item | Score | F Item | Score |
|---|---|---|---|---|---|---|---|
| 8 | 5 , 6 , 9 | 17 | 5 , 5 , 7.5 | 33 | 6 , 6 , 15 | 13 | 6 , 6 , 15 |
| 29 | 6 , 6 , 15 | 18 | 5 , 5 , 7.5 | 36 | 6 , 6 , 15 | 12 | 5 , 5 , 7.5 |
| 19 | 5 , 5 , 7.5 | 16 | 6 , 5 , 12.5 | 34 | 6 , 6 , 15 | 10 | 5 , 5 , 7.5 |
| 28 | 5 , 6 , 9 | 27 | 5 , 5 , 7.5 | 32 | 5 , 5 , 7.5 | 11 | n/a |
| 7 | 5 , 5 , 7.5 | 23 | 5 , 5 , 7.5 | 30 | 6 , 5 , 12.5 | | |
| 1 | 5 , 5 , 7.5 | 26 | 5 , 5 , 7.5 | 35 | 5 , 5 , 7.5 | | |
| 2 | 6 , 5 , 12.5 | 22 | 6 , 4 , 10 | 31 | 6 , 5 , 12.5 | | |
| 14 | 5 , 4 , 6 | 25 | 2 , 5 , -7.5 | | | | |
| 15 | 6 , 4 , 10 | 24 | n/a | | | | |
| 20 | 5 , 5 , 7.5 | | | | | | |
| 21 | 5 , 4 , 6 | | | | | | |
| 6 | 5 , 6 , 9 | | | | | | |
| 9 | 5 , 4 , 6 | | | | | | |
| 3 | 4 , 4 , 2 | | | | | | |
| 4 | 3 , 4 , -2 | | | | | | |
| 5 | 2 , 2 , -3 | | | | | | |

**Participant #9**

| H& F Item | Score | S&E Item | Score | P&S Item | Score | F Item | Score |
|---|---|---|---|---|---|---|---|
| 1 | 4 , 6 , 3 | 24 | 6 , 6 , 15 | 32 | 6 , 6 , 15 | 12 | 6 , 6 , 15 |
| 29 | 5 , 6 , 9 | 27 | 4 , 6 , 3 | 31 | 6 , 6 , 15 | 10 | 5 , 6 , 9 |
| 5 | 3 , 6 , -3 | 26 | 6 , 6 , 15 | 33 | 4 , 4 , 2 | 13 | n/a |
| 7 | 5 , 5 , 7.5 | 17 | 6 , 6 , 15 | 30 | 5 , 6 , 9 | 11 | n/a |
| 6 | 4 , 4 , 2 | 23 | 6 , 6 , 15 | 35 | 4 , 5 , 2.5 | | |
| 2 | 5 , 6 , 9 | 16 | 5 , 4 , 6 | 34 | 5 , 6 , 9 | | |
| 20 | 4 , 6 , 3 | 18 | 4 , 3 , 1.5 | 36 | 5 , 4 , 6 | | |
| 8 | 3 , 6 , -3 | 22 | 6 , 3 , 7.5 | | | | |
| 21 | 3 , 2 , -1 | 25 | n/a | | | | |
| 19 | 3 , 6 , -3 | | | | | | |
| 28 | 3 , 4 , -2 | | | | | | |
| 3 | 6 , 4 , 10 | | | | | | |
| 9 | 4 , 3 , 1.5 | | | | | | |
| 4 | 5 , 4 , 6 | | | | | | |
| 15 | 1 , 6 , -15 | | | | | | |
| 14 | 1 , 6 , -15 | | | | | | |

**Participant #10**

| H& F Item | Score | S&E Item | Score | P&S Item | Score | F Item | Score |
|---|---|---|---|---|---|---|---|
| 19 | 3 | 17 | 5 , 6 , 9 | 31 | 5 , 6 , 9 | 11 | 6 , 6 , 15 |
| 5 | 9 | 18 | 4 , 6 , 3 | 30 | 4 , 6 , 3 | 10 | 5 , 6 , 9 |
| 7 | 7.5 | 16 | 6 , 6 , 15 | 33 | 4 , 5 , 2.5 | 13 | 6 , 6 , 15 |
| 8 | 15 | 22 | 6 , 6, 15 | 32 | 4 , 5 , 2.5 | 12 | 5 , 6 , 9 |
| 6 | 7.5 | 27 | 6 , 6 , 15 | 34 | 3 , 6 , -3 | | |
| 29 | 9 | 26 | 3 , 6 , -3 | 35 | 5 , 5 , 7.5 | | |
| 20 | 7.5 | 23 | 3 , 4 , -2 | 36 | 6 , 6 , 15 | | |
| 14 | 9 | 25 | 2 , 3 , -4.5 | | n/a | | |
| 1 | 3 | 24 | n/a | | | | |
| 28 | 9 | | | | | | |
| 21 | 2 | | | | | | |
| 3 | -3 | | | | | | |
| 2 | -9 | | | | | | |
| 4 | 2.5 | | | | | | |
| 15 | 2 | | | | | | |
| 9 | -9 | | | | | | |

**Participant #11**

| H& F Item | Score | S&E Item | Score | P&S Item | Score | F Item | Score |
|---|---|---|---|---|---|---|---|
| 5 | 5 , 6 , 9 | 27 | 6 , 6 , 15 | 35 | 5 , 6 , 9 | 13 | 6 , 6 , 15 |
| 6 | 6 , 6 , 15 | 23 | 6 , 6 , 15 | 34 | 4 , 5 , 2.5 | 10 | 5 , 6 , 9 |
| 8 | 6 , 6 , 15 | 17 | 6 , 4 , 10 | 32 | 4 , 6 , 3 | 12 | 4 , 5 , 2.5 |
| 28 | 5 , 6 , 9 | 25 | 5 , 4 , 6 | 31 | 6 , 6 , 15 | 11 | 1 , 1 , -2.5 |
| 29 | 4 , 6 , 3 | 18 | 5 , 3 , 4.5 | 33 | 4 , 6 , 3 | | |
| 3 | 5 , 6 , 9 | 16 | 3 , 5 , -2.5 | 36 | 4 , 5 , 2.5 | | |
| 7 | 6 , 6 , 15 | 22 | 4 , 4 , 2 | 30 | 4 , 6 , 3 | | |
| 21 | 4 , 6 , 3 | 26 | 3 , 4 , -2 | | | | |
| 19 | 5 , 5 , 7.5 | | | | | | |
| 14 | 3 , 6 , -3 | | | | | | |
| 15 | 1 , 6 , -15 | | | | | | |
| 9 | 4 , 6 , 3 | | | | | | |
| 1 | 4 , 4 , 2 | | | | | | |
| 2 | 5 , 6 , 9 | | | | | | |
| 20 | 3 , 4 , -2 | | | | | | |
| 4 | 6 , 6 , 15 | | | | | | |

## **Appendix T** Analyses of the Effects of the Intervening Variables for Phase 2

### Summary of Oneway ANOVA for QLI Score by Gender

| Source | Sum of Squares | df | Mean Square | F | Significance of F |
|---|---|---|---|---|---|
| Between Groups | 4.18 | 1 | 4.18 | .23 | .64 |
| Within Groups | 1767.69 | 96 | 18.41 | | |
| Total | 1771.87 | 97 | | | |

### Summary of Oneway ANOVA for QLI Score by Level of Injury

| Source | Sum of Squares | df | Mean Square | F | Significance of F |
|---|---|---|---|---|---|
| Between Groups | 14.09 | 1 | 14.09 | .77 | .38 |
| Within Groups | 1757.77 | 96 | 18.31 | | |
| Total | 1771.87 | 97 | | | |

### Summary of Oneway ANOVA for QLI Score by Employment Status

| Source | Sum of Squares | df | Mean Square | F | Significance of F |
|---|---|---|---|---|---|
| Between Groups | 112.04 | 3 | 37.35 | 2.115 | .10 |
| Within Groups | 1659.83 | 94 | 17.66 | | |
| Total | 1771.87 | 97 | | | |

### Summary of Oneway ANOVA for QLI Score by Marital Status

| Source | Sum of Squares | df | Mean Square | F | Significance of F |
|---|---|---|---|---|---|
| Between Groups | 31.67 | 3 | 10.56 | .57 | .64 |
| Within Groups | 1740.19 | 94 | 18.51 | | |
| Total | 1771.87 | 97 | | | |

### Summary of Oneway ANOVA for QLI Score by Living Arrangements

| Source | Sum of Squares | df | Mean Square | F | Significance of F |
|---|---|---|---|---|---|
| Between Groups | 40.53 | 3 | 13.51 | .73 | .54 |
| Within Groups | 1731.34 | 94 | 18.42 | | |
| Total | 1771.87 | 97 | | | |

### Summary of Oneway ANOVA for QLI Score by Educational Status

| Source | Sum of Squares | df | Mean Square | F | Significance of F |
|---|---|---|---|---|---|
| Between Groups | 49.45 | 4 | 12.36 | .67 | .62 |
| Within Groups | 1722.42 | 93 | 18.52 | | |
| Total | 1771.87 | 97 | | | |

## **Appendix U** Analyses of the Effects of the Intervening Variables for Phase 3

### Summary of Oneway ANOVA for QLI Score by Gender

| Source | Sum of Squares | df | Mean Square | F | Significance of F |
|---|---|---|---|---|---|
| Between Groups | 6.49 | 1 | 6.49 | .46 | .51 |
| Within Groups | 499.21 | 35 | 14.26 | | |
| Total | 505.69 | 36 | | | |

### Summary of Oneway ANOVA for QLI Score by Level of Injury

| Source | Sum of Squares | df | Mean Square | F | Significance of F |
|---|---|---|---|---|---|
| Between Groups | 4.28 | 1 | 4.28 | .29 | .59 |
| Within Groups | 501.41 | 35 | 14.33 | | |
| Total | 505.69 | 36 | | | |

### Summary of Oneway ANOVA for QLI Score by Employment Status

| Source | Sum of Squares | df | Mean Square | F | Significance of F |
|---|---|---|---|---|---|
| Between Groups | 52.61 | 3 | 17.54 | 1.28 | .29 |
| Within Groups | 453.08 | 33 | 13.73 | | |
| Total | 505.69 | 36 | | | |

### Summary of Oneway ANOVA for QLI Score by Marital Status

| Source | Sum of Squares | df | Mean Square | F | Significance of F |
|---|---|---|---|---|---|
| Between Groups | 15.56 | 1 | 15.56 | 1.11 | .29 |
| Within Groups | 490.13 | 35 | | | |
| Total | 505.69 | 36 | | | |

### Summary of Oneway ANOVA for QLI Score by Living Arrangements

| Source | Sum of Squares | df | Mean Square | F | Significance of F |
|---|---|---|---|---|---|
| Between Groups | 79.30 | 3 | 26.43 | 2.05 | .13 |
| Within Groups | 426.39 | 33 | 12.92 | | |
| Total | 505.69 | 36 | | | |

### Summary of Oneway ANOVA for QLI Score by Educational Status

| Source | Sum of Squares | df | Mean Square | F | Significance of F |
|---|---|---|---|---|---|
| Between Groups | 99.91 | 8 | 12.49 | .862 | .56 |
| Within Groups | 405.78 | 28 | 14.49 | | |
| Total | 505.69 | 36 | | | |